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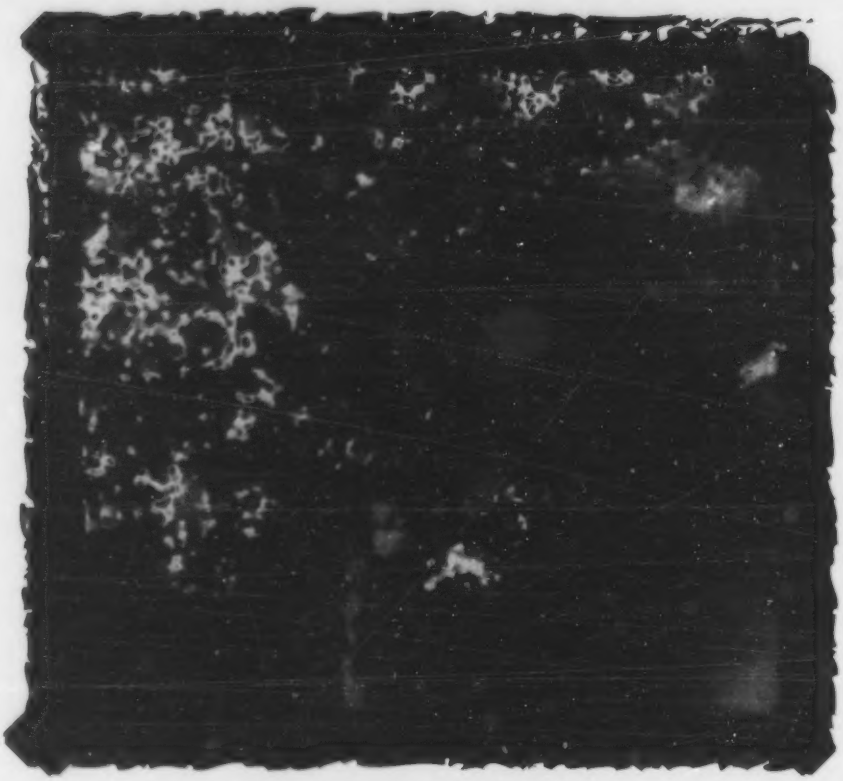
SITUATIONAL ANALYSIS



Fetal Alcohol Syndrome/ Fetal Alcohol Effects and the Effects of Other Substance Use During Pregnancy

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Ce document est aussi offert en français sous le titre : *Analyse de la situation – Syndrome d'alcoolisme foetal/effets de l'alcool sur le foetus et les effets des autres drogues pendant la grossesse*

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Minister of Public Works and Government Services Canada, 2001
Cat. No. H49-156/2-2001E
ISBN 0-662-85707-0

101-05786

Situational Analysis
Fetal Alcohol Syndrome/Fetal Alcohol Effects and the Effects of Other Substance Use During Pregnancy

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December 2000

canada's drug strategy

Acknowledgements

During the course of this project, the principal investigator, Carole Legge, became ill and sadly died on December 4, 2000. Carole became involved with this project to further the knowledge on substance use and pregnancy in Canada. Her commitment to issues related to fetal alcohol syndrome will be greatly missed by colleagues across the country. This report is dedicated to her.

Thanks are expressed to Susan Rosidi of Canadian Centre on Substance Abuse (CCSA) for managing the mail-out program survey, Jill Austin (CCSA) for preparing statistical analyses, Virginia Thomas for conducting the French language and Aboriginal interviews, and to Richard Garlick (CCSA) for editing this report. Appreciation is also expressed to the project steering committee members for their guidance and support throughout the project. Finally, thanks are extended to the many persons who gave their time to share information with the project as key informants or program survey respondents.

The findings of this report reflect the results of a survey completed in November 1999. Since that time, several provinces and territories have implemented other FAS/FAE-related programs. Therefore, it has not been possible to account for all subsequent initiatives. The information presented is based on the responses of key informants and this has resulted in some limitations to the results. Please contact your provincial and territorial government for further information.

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1. Introduction

Alcohol and other substance use during pregnancy is a problem inseparable from many other issues and factors in the lives of mothers, children, their families and communities. Although Fetal Alcohol Syndrome (FAS), Fetal Alcohol Effects (FAE) and the effects from other substance use during pregnancy are preventable, solutions are complex and must be viewed from a broad-based context that requires commitment and long-term planning on the part of many (Health Canada, 1996).

The effects from alcohol use during pregnancy vary with the timing, amount and duration of alcohol consumption, the general health of the mother and the resources available, but can result in FAS/FAE. Epidemiological research into FAS/FAE is incomplete, but the associated human and economic costs are significant and lifelong, as it is a leading cause of mental disability and preventable birth defects.

The effects of other substances e.g. cannabis, opiates, inhalants, etc., during pregnancy are less well understood but thought nonetheless to be significant. These effects also vary with the manner of use and the health and social circumstances of the mother.

1.1 Context and Project Purpose

In the spring of 1999, the Canadian Centre on Substance Abuse (CCSA) undertook this situational analysis project on Fetal Alcohol Syndrome/Fetal Alcohol Effects and the effects of other substance use during pregnancy for Health Canada. This project was supported by a national steering committee and involved a review of FAS/FAE-related activity across Canada, based on the results of key informant interviews and a survey of programs to December, 1999. This analysis will follow a life-span approach.

1.2 Organization of the Document

The following section will describe the methodology used for the key informant interviews and the mailed surveys. A profile of activity across Canada will be discussed. The profile will be organized according to the primary categories as defined in Section 2.2.1:

- Prevention
- Identification
- Intervention

The following categories will be discussed in support of the primary categories:

- Community and systems supports
- Research
- Policy

A listing of the issues identified by key informants with respect to the above topic areas will be presented. It is important to note that specific initiatives cited in this discussion are presented only as examples of activities to illustrate a trend or pattern.

The sections entitled Profile of Activities and List of Resources present a more complete list of activities and resources, broken down by jurisdiction.

A list of members of the steering committee for this project and a copy of the interview questions can be found in the Appendices.

Data collection for this analysis was finished in December, 1999. Since then, further developments have occurred. It is not possible to account for all recent initiatives; however, some of the more significant include:

- The Prairie Province Partnership on FAS was expanded in 2000 to include the Yukon, Nunavut and Northwest Territories, and became the Prairie Northern FAS Partnership;[1]
- The Correctional Service of Canada's National Headquarters Working Group on FAS/FAE;
- The federal government's National Advisory Committee on FAS/FAE coordinated by Health Canada;
- The Motherisk Program newsletter Fall 2000 (#12) that is fully dedicated to FAS/FAE research;
- Health Canada's National First Nations and Inuit CPNP/FAS/E Steering Committee held regional discussion and feedback sessions resulting in the development of a National Framework for the First Nations and Inuit FAS/FAE Initiative.
- Health Canada's Childhood and Youth Division of Population and Public Health Branch held regional discussion and feedback sessions across Canada.
- January 2000, Health Canada announced an $11 million initiative for FAS/FAE to build on the work of partners at the provincial, territorial and community levels.

It should also be noted that a related Health Canada project, Enhancing FAS/ARBD Interventions at the Prenatal and Early Childhood Stages in Canada, provides information on best practices, and funding for the Community Action Program for Children (CAPC), Canada Prenatal Nutrition Program (CPNP) and Aboriginal Headstart Program (AHS).

1 Prairie Northern FAS Partnership will be used throughout this document.

2. Methodology

2.1 Key Informant Interviews

2.1.1 Selection of Key Informants

Nominations for key informants were received from 1) members of the steering committee, 2) the Federal/Provincial/Territorial Committee on Alcohol and Other Drug Issues, 3) provincial FAS coordinators (where they existed), and 4) Health Canada. As well as representing the 13 provincial/territorial jurisdictions, other considerations in the selection of key informants were:

- multidisciplinary coverage (i.e., medicine, addictions, social services, psychology);
- coverage of the life stages;
- representation of a variety of work settings (i.e., academia, government, community agencies);
- perspective of a parent of an affected child;
- representation of Aboriginal issues; and
- inclusion of individuals who could articulate the major issues facing remote and rural communities.

Twenty-eight people were selected. Two nominees declined; both recommended a more suitable colleague. In three cases, two people participated in the interview, making a total of 31 key informants. A series of 28 interviews were then carried out to collect information on FAS/FAE-related activities in each of the key informant's jurisdictions.

2.1.2 Interviews

All participants were sent a confirmation letter as well as an interview guide that included a set of open-ended interview questions (see Appendix A) and key definitions (see Section 2.2.1). The interview guide was tested prior to initiating the interviews.

In preparing for and answering the questions, interviewees were asked to present a broad jurisdictional perspective. Informants were encouraged to contact at least two other people to complement their knowledge of FAS/FAE-related activities in their jurisdiction. Together, this canvassing resulted in input from an additional 21 people being incorporated into the data collection process.

All interviews were conducted by telephone; 24 were in English and the remaining 4 in French. To ensure appropriate representation of Aboriginal views, 6 interviews were conducted with members of the Aboriginal community. Interviews took place between August and November, 1999. Interview times ranged from 40-90 minutes.

The French interviews were translated into English for the purpose of data analysis. Information collected from the program survey and key informant interviews was analyzed for common themes and trends.

2.2 Program Survey

CCSA's FAS/FAE database formed the basis of the sample for the program survey. The 250 agencies in CCSA's database of treatment agencies, that indicated specialized services for women, were sent the program survey. Steering committee members and provincial FAS coordinators were invited to suggest other agencies that provide services for women, taking into account the following: 1) the organization is currently, or has within the past five years been involved in FAS/FAE activities, 2) has received outside funding to specifically address FAS/FAE-related issues, or 3) identifies FAS/FAE issues specifically in their mandate.

The total number of surveys sent out was 605 and 239 were returned, for a response rate of 39%. Seventy-five per cent indicated that the overall focus of their organization was either health or children/family services.

Table 1: Jurisdictional Breakdown of Original Sample and Those Responding

Jurisdiction	Surveyed	Responded
British Columbia	136	56
Alberta	121	48
Saskatchewan	60	29
Manitoba	102	33
Ontario	89	40
Quebec	45	9
New Brunswick	8	4
Nova Scotia	6	3
Prince Edward Island	4	2
Newfoundland	11	6
Yukon	13	5
Northwest Territories	10	4
Total	**605**	**239**

Figure 1: Focus of Responding Organizations (respondents checked all that applied)

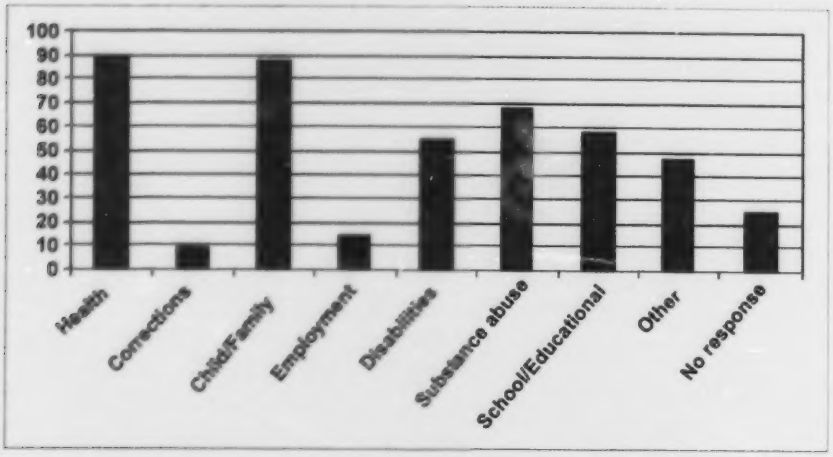


Table 2: Scope of Activities of Responding Organizations

Scope	Respondents
National	19
Regional	16
Province/Territory	106
Urban	108
Rural	100

2.2.1 Defining FAS/FAE-related Activities

For the purposes of this project, the following definitions were developed:

Prevention activities address issues up to the birth of the child and are intended to promote health, prevent alcohol and other drug use during pregnancy, prevent conception while substances are used, or reduce the harm arising from substance use during pregnancy.

Primary prevention activities are undertaken with a healthy population to maintain or enhance physical and/or emotional health. Such activities focus on individual behaviour change, systems or environments. Examples of primary prevention activities include raising public awareness, community education and alcohol control measures.

Secondary prevention activities aim to address a problem before it becomes severe or persistent. Examples of secondary prevention activities include outreach, screening and referral for women who are pregnant, or of child-bearing age, and using substances.

Tertiary prevention activities are for individuals in whom the condition has already developed. Activities include providing substance abuse treatment or birth control services for women who are at-risk of having a child affected by prenatal substance use, or women who have already given birth to a FAS/FAE or other substance use affected child.

Identification activities that involve screening, referral and diagnosis of newborns, children, adolescents or adults affected by prenatal substance use. Screening may occur within a variety of settings such as social and health care, legal, educational or vocational. Diagnosis is carried out by medical specialists in conjunction with multidisciplinary teams. Assessment may occur prior to or following diagnosis, and in either case, elaborates on the person's abilities and attributes beyond that provided by a diagnosis.

Intervention activities are intended to prevent or reduce the harm associated with primary and secondary disabilities. These activities are directed to individuals with FAS/FAE or other drug effects, including infants, children, adolescents and adults. Examples of such activities include strategies for improving management of the child, parenting, family support, or special interventions with respect to schools, vocational training, young offenders, or criminal justice settings.

2.2.2 Limitations

When considering the findings of this analysis, the following limitations should be noted:

- Considering the national scope of this project and the breadth and complexity of the issues, the sample size of the key informant interviews was small.
- The scope of reported activities is limited to the information provided by key informants and mailed survey respondents. Some important activities may have been missed.
- The mail survey sample was broad and included many general social, health and education organizations; the response rate of 39%.
- Not every informant consulted with others prior to their interview, which was encouraged.
- Different interviewers were used for English-speaking, French-speaking and Aboriginal key informants. In some cases, this may have influenced the information obtained from the interviews.

- The use of substances by pregnant women and women of child-bearing age is interwoven with many other health, social, cultural and economic issues. It was beyond the scope of this project to investigate these broader issues.

3. Findings

3.1 Profile of Activities Across Canada

This section provides a synthesis of the results of the key informant and program surveys. The information gathered through the program surveys served to clarify and expand on the data gathered from the key informant interviews.

3.1.1 Extent of Activities

Across Canada, the level of prevention, identification and intervention activity varies; however, there is a clear pattern of greater activity occurring west of Ontario. Seventy-two per cent of the 239 organizations that responded to the program survey were from the western provinces and territories. British Columbia appears to have been the most active jurisdiction in the country on this issue. The Prairie Northern FAS Partnership, a strategy to address FAS/FAE, has greatly increased activities in Alberta, Saskatchewan, Manitoba, Yukon, Nunavut and Northwest Territories.

3.1.2 Type of Activities

Prevention is the most prevalent activity (particularly primary prevention activities such as public awareness, public education and information dissemination), occurring in every province and territory.

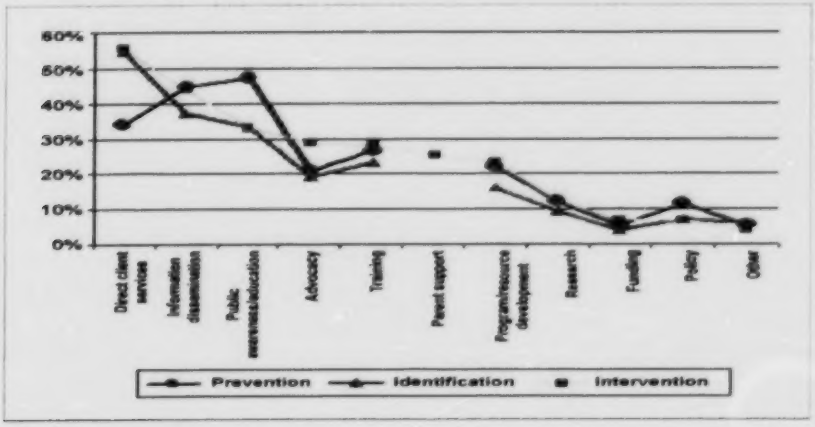
In British Columbia, Alberta, Saskatchewan and Manitoba, provincial government funding and technical support has helped develop infrastructures to support community initiatives. Fifty-one percent of survey respondents indicated involvement in local coalitions or committees addressing FAS/FAE-related issues.

Public awareness and information dissemination are the two predominant activities for organizations describing their FAS/FAE work as prevention, while direct client service and information dissemination are the two main activities for organizations that describe their work as identification or intervention. Respondents clearly indicated that there is a lack of activity occurring across jurisdictions, with the exception of the Prairie Northern FAS Partnership.

Some respondents, who identified themselves as working in corrections, law enforcement, judicial or employment systems, indicated they were engaged in FAS/FAE-related activities; however, they reported few activities within these systems.

While the education system in some jurisdictions is beginning to respond to the needs of students with FAS/FAE, respondents felt that the education system may not be adequately meeting the demands for assessment, individualized learning plans and teacher assistance in the classroom. Many key informants noted that the educational experience of children with FAS/FAE is likely to be a critical influence over the course of their lives.

Figure 2: Prevention, Identification and Intervention Activities



3.1.3 Population Groups Served

The majority of organizations (50% to 60%) indicated that women in general, women of child-bearing age and pregnant women were the main focus of their prevention activities, followed by adolescents, young adults, adults, families and the community.

The major population groups served by organizations engaged in identification and intervention activities were children 0 to 6 years of age, followed by adolescents and young adults.

Nearly half of survey respondents indicated that they provided intervention services for adolescents, with the same number indicating they provided these services for young adults. The key informants noted that there are few programs (in areas of addictions, pre-employment and employment training) that are developed and available to address the unique behavioural, social and adaptive life skills problems of adolescents and adults with FAS/FAE.

3.1.4 Organizations

While 95% of the agencies and organizations indicated a strong ongoing interest in FAS/FAE, the mandate of most (77%) did not focus solely on FAS/FAE-related issues. Most of these organizations operate at provincial, territorial or community levels. While national leadership was in evidence in 1996 with the signing of the *Joint Statement: Prevention of Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects(FAE) in*

Canada by 18 national organizations, key informants noted the lack of national organizations currently involved with FAS/FAE and reported the need for more national leadership and advocacy.

Respondents felt that leadership and advocacy historically originated mainly from parents and a small group of professionals who advocated on behalf of individuals with FAS/FAE for more research, programs and services, and for changes within the health, social services, justice and employment systems.

Parents, particularly foster and adoptive parents, have been and continue to be key catalysts for action. Parents contribute to the education of professionals in all fields on issues pertaining to living with and caring for a FAS/FAE-affected child. Many are involved in activities to increase public awareness and to press for needed services in their own jurisdictions. The "parent movement" consists of individuals, grassroots groups and some formalized organizations. Examples of these initiatives include: the FAS/E Support Network of BC; Special Needs Adoptive Parents (SNAP) in BC; the Adoption Council of Canada; Syndrome d'alcoolisation foetal et effets reliés à l'alcool (SAFERA) in Quebec; FASLink now moderated through the Fetal Alcohol Support Network (Toronto and Peel); olderFAS for parents of adolescents and young adults; the Teaching and Research for the Identification, Understanding and Management of Fetal Alcohol Syndrome (TRIUMF) Project; Fetal Alcohol Syndrome Society of the Yukon (FASSY); Association for Community Living in Manitoba; and the International FAS Day. For the most part, parent-based action lacks coordination within provinces/ territories and nationally.

The respondents noted that federal leadership was most evident in the area of children's programs funded by Health Canada (e.g., CAPC, CPNP, and AHS) and managed in partnership with the provinces and territories. In the 1999 budget, the federal government provided $11 million dollars to enhance FAS/FAE activities in a number of areas, including public awareness, education, surveillance, early identification, diagnosis, FAS/FAE-related training and strategic project funding. In May 2000, Health Canada struck a National Advisory Committee on FAS/FAE to provide strategic advice and expertise to Health Canada with priority attention to the implementation of the 1999 budget commitment.

Health Canada hosted its first National Forum on FAS/FAE on May 25th 1999. The purpose of the forum was to provide an opportunity for participants from governments and national, provincial and local organizations and associations to learn about new and innovative approaches to addressing fetal alcohol syndrome/fetal alcohol effects and other substance use during pregnancy.

Health Canada will be hosting its 2nd National Forum in the fall of 2001. The purpose is to develop a national action plan for FAS/FAE that will include all levels of involvement (national, provincial, regional and community) as well as the relevant sectors (i.e. education, health, social services, justice, corrections).

The level of leadership by provincial/territorial governments varies across the country. The governments of the western provinces and territories are involved and have recognized FAS/FAE as a priority issue. The Prairie Northern FAS Partnership involving a partnership between Alberta, Saskatchewan, Manitoba, Yukon, Nunavut and the Northwest Territories, is a notable example of provincial leadership and collaboration.

Many Aboriginal communities across Canada have implemented public awareness and education initiatives. Aboriginal leaders have led conferences, workshops and train-the-trainer sessions, and instituted a national certification course in an effort to increase the level of understanding of FAS/FAE. Saskatchewan has provided community grants to support Aboriginal communities to take action on FAS/FAE. Some of the best examples of health promotion-based initiatives, such as the Community Healing and Intervention Program in BC (CHIP), have been developed by and implemented in Aboriginal communities. However, as with the general pattern of activities across Canada, most of the activities in Aboriginal communities are localized and instigated on a community-by-community basis.

Among professional groups in Canada, health professionals are most likely to be involved in addressing FAS/FAE issues. However, social service professionals are becoming more involved. Professionals within the education and correction systems in some jurisdictions are also recognizing the need to respond to the needs of people with FAS/FAE, although key informants point out there is still work to be done in these areas.

There is also a growing interest in addressing FAS/FAE issues at the community level, although the interest is uneven across jurisdictions, and communities within those jurisdictions are at varying stages of development. The agencies and groups that have been working on this issue for a number of years are involved in coordination activities, extensive networking, support measures, policy development, and adapting services to meet needs. In contrast, those at earlier stages of community development are working hard to raise public, professional and political awareness.

3.2 Description of Key Activities

In the following section, activities are discussed in terms of six broad categories: prevention, identification, intervention, community/systems supports, research and policy. Tables 3 and 4 identify prevention and identification activities respectively in the provinces and territories; however, they do not provide information on the number, availability, scope or quality of the activities reported.

3.2.1 Prevention Activities

The following section will expand upon primary, secondary and tertiary prevention activities.

Table 3: Jurisdictional Profile of FAS/FAE-related Activities: Prevention

Identified Prevention Activities	YK	NT	NU	BC	AB	SK	MB	ON	PQ	NB	NS	PEI	NF
1. Public awareness campaigns:													
► Provincially directed campaigns using print and media resources	✔				✔	✔	✔	✔					✔
► Local community public awareness initiatives using local media, print materials and special events	✔	✔	✔	✔	✔	✔	✔	✔			✔		✔
2. Information dissemination:													
► Information phone lines for a range of information on FAS/FAE and support		✔		✔	✔		✔	✔	✔				
► Locally developed resource materials distributed through social service agencies, clinics, health units	✔	✔		✔	✔	✔	✔	✔		✔	✔		
3. Public education:													
► Information-based sessions such as workshops, conferences and forums presented to a cross section of professionals, frontline workers and other community members	✔			✔	✔	✔	✔	✔	✔		✔		✔
4. Community-based projects that use a variety of strategies, including community development, to inform the public about FAS/FAE and to change public attitudes	✔			✔	✔	✔	✔	✔			✔		
5. Identification and referral of pregnant substance-using women to appropriate treatment and/or counselling programs	✔	✔		✔	✔	✔	✔	✔	✔		✔	✔	
6. Support program for women using substances during pregnancy	✔	✔		✔	✔	✔	✔	✔	✔		✔		
7. Legislated warning labels on alcoholic beverages	✔												
8. Warning signage about alcohol and pregnancy posted in establishments selling/serving alcoholic beverages				✔		✔	✔						

3.2.2 Primary Prevention Activities

a) Public Awareness Campaigns

Public awareness campaigns have been initiated at both the provincial/territorial and local levels across the country. Prevention messages focus primarily on influencing women of child-bearing age not to drink during pregnancy, by pointing out the harm that can occur to the developing fetus. Some messages promote positive actions that women can take to ensure their best health and that of their baby, or emphasize the supportive role that partners, families and communities can play during pregnancy. Both local and provincial campaigns use printed materials and print media resources, but use of radio and television tends to be limited to provincial-level campaigns due to the costs involved.

Provincial/territorial-level campaigns tend to be more comprehensive, offer broader exposure and convey consistent messaging over a longer period of time than local campaigns. A three-year public awareness campaign now underway is part of the Prairie Northern FAS Partnership. The three founding provinces have developed public awareness materials, including radio and television commercials, posters and brochures that have been circulated across these provinces. In Alberta, for example, the two main prevention messages are, "When you are pregnant, no alcohol is best", and "Fetal Alcohol Syndrome is 100% preventable." In the Northwest Territories, a campaign that includes two television advertisements and a booklet, "Hearing the Voices of Birth Parents in Recovery", is underway.

Local community public awareness initiatives using media, print materials and special events are common across jurisdictions. Often the campaigns consist of a public forum, displays at health fairs, interviews on local radio talk shows, articles in local newspapers, distribution of pamphlets, and in some cases, local television public service announcements (PSAs). Some communities have used nationally or provincially designated weeks/days, such as National Drug/Addiction Awareness Week or International FAS Day as a rallying point for their awareness activities.

b) Warning Signage and Labels

The Yukon is the only jurisdiction that has warning labels on alcohol beverages sold within its borders. A few jurisdictions have promoted the posting of warning signage on the dangers of drinking during pregnancy in establishments selling/serving alcohol beverages. For example, Manitoba's Liquor Control Commission has produced alcohol warning signs to be voluntarily placed in such locations. Community groups in over 50 BC municipalities have lobbied successfully for local by-laws requiring establishments selling or serving alcohol beverages to post warning signs.

c) Information Dissemination

Many jurisdictions have developed and are distributing print materials (e.g., pamphlets, booklets, posters, fact sheets and calendars) through a variety of professional associations, service agencies, clinics, health units and community organizations. In some cases, information is accessed electronically through provincial Web sites. One FAS/FAE-specific Web site is managed from Lethbridge, Alberta, another by the SAFERA parent association in Quebec. Prevention Source BC provides information on a range of FAS/FAE topics. Other Web sites include CCSA's national FAS/FAE Information Service (http://www.ccsa.ca/fasgen) and Health Canada's site (http://www.hc-sc.gc.ca). The FASLINK lists, managed by the FAS Support Network in Toronto, is available via e-mail. As well, a number of provincial organizations provide FAS/FAE-related information and publications through their government Web sites.

Some jurisdictions offer FAS/FAE-specific information through telephone lines. The CCSA, through its National Clearinghouse on Substance Abuse, operates a 1-800 number FAS/FAE Information Service. The information service also responds to fax, e-mail and written requests, with a range of information about prevention, identification and intervention in connection with FAS/FAE and related effects. The Addictions Foundation of Manitoba sponsors an FAS/FAE phone line, and a resource library available to professionals and the public. In BC, 12 organizations offer phone and/or resource library services on FAS/FAE. They coordinate their efforts through the FAS Information Service Providers Committee. The committee tracks requests using a standardized form, and publishes a yearly report, "Who's Asking? Measuring the Demand for FAS Information in BC."

In Kingston, Ontario, the Action on Women's Addictions, Research and Education (AWARE) Program has developed a booklet and resource kit called, "Give and Take". The kit was written by professional women and women who had substance use problems. It is intended to help women prevent substance use problems during pregnancy. Both Alberta and BC have adapted the booklet for their use and have distributed it widely throughout their provinces.

d) Public Education

The primary purpose of public and community education is to increase the understanding of FAS/FAE, and to encourage community groups and individuals to take action. Community education often takes the form of presentations to community groups, community workshops, forums and conferences. The audience for public education usually involves a mix of professionals, parents and other interested members of the public. Most jurisdictions across Canada reported a variety of public education initiatives taking place at the community level. As the opportunities for education on FAS/FAE are limited, many of the local conferences also draw people from other locales within their province and from other provinces. A number of communities have strategically used FAS/FAE conferences to not only increase

understanding of FAS/FAE, but also as vehicles to mobilize communities to take action. In BC over the past five years, such a community-based conferencing model has spawned the establishment of FAS/FAE community action teams.

Subsequent to the first known meeting in Canada on FAS/FAE held in Vancouver in 1973, provincial symposia and conferences have contributed significantly to jurisdictional understanding and action. In the early 1990s, Halifax and St. John's each hosted a symposium on the prevention of FAS/FAE. During the past 10 years, BC has held a bi-annual provincial conference on FAS/FAE highlighting the latest FAS/FAE programs, projects and research available. As part of the Prairie Northern FAS Partnership, Alberta, Manitoba and Saskatchewan each take the lead in hosting an annual FAS/FAE conference. BC and Alberta together have organized a conference looking specifically at issues facing high-risk women.

e) Community-based Projects

Community-based projects that use a variety of strategies are most prevalent in western Canada. The nature and focus of these projects differ across jurisdictions. Each of the initial three provinces involved in the Prairie Northern FAS Partnership has established a community grants program. Nearly $700,000 in seed money was invested in the first year of the initiative by the three provinces for local prevention projects, and to enhance community capacity and partnerships. In Alberta, funds were distributed to regions to develop and carry out strategic plans. Additionally, Alberta funded pilot projects targeting women at high risk of giving birth to an FAS/FAE child. In Saskatchewan, projects that focus on increasing awareness, understanding and prevention, mainly in Aboriginal communities, are under way. In Manitoba, community awareness and prevention projects have been funded.

In BC, volunteer-based community groups are pursuing a wide range of prevention initiatives. The Community Healing and Intervention Program (CHIP) is a six year old, comprehensive health promotion program. CHIP uses the strategies outlined in the Health Promotion Framework developed by Health Canada as a basis for a comprehensive approach to FAS/FAE among communities of the Kinbasket First Nations.

3.2.3 Secondary and Tertiary Prevention Activities

Most provinces and territories have some programming in place for women identified as high-risk or who are pregnant and using substances. Programs funded by provincial/territorial governments, such as pregnancy outreach and healthy baby programs, and federally funded CAPC and CPNP programs, have mandates that permit them to be involved in identification of high-risk women.

Routine screening to identify women who may be at risk of having a child born with alcohol-related difficulties is considered an important secondary prevention activity. While some screening activities are evident in most jurisdictions, routine and uniform screening is less prevalent and just beginning to occur in other jurisdictions. There are

a number of standardized screening tools used, including T-ACE, CAGE and TWEAK. A new prenatal psychosocial health assessment tool has been developed and is being used by Prince Edward Island physicians. The tool is based on the ALPHA tool from Ontario and includes a number of questions on alcohol and drug use during pregnancy. Evaluation to assess its effectiveness is planned. Alcohol and Drug Services in the Yukon has been working with physicians and nurses in their communities to train and encourage them to use T-ACE or TWEAK.

Respondents report that there are relatively few addiction treatment and counselling services that offer appropriate, women-centred approaches for pregnant substance-using women. The 250 agencies reporting specialized services for women in CCSA's database of treatment agencies were included in the program survey. Almost all of the 68 treatment agencies responding indicated that they provided priority admission to pregnant women, while approximately half of them reported providing detoxification services for pregnant women.

Sheway in Vancouver and Breaking the Cycle in Toronto are examples of "one-stop" programs that offer a number of services, including access to treatment for women who are pregnant and using substances. Both offer comprehensive, integrated and continuous service pre- and post-natally. Sheway provides both practical support to women to address basic needs (such as daily hot nutritious lunches, food coupons and food bank hampers, nutritional supplements, bus tickets, formula, and diapers) and professional services offered by a multidisciplinary staff, some of whom provide on-site assessment and care. Breaking the Cycle has similar services directed to mothers in difficult circumstances with children under the age of six.

In Manitoba, the STOP FAS Program uses a home visitation model of enhanced case management to work with at-risk women who are pregnant and using alcohol and other drugs. Paraprofessional mentors work with the women for three years to address substance use and related issues. In cooperation with the Manitoba sponsors, the Alberta government is planning to introduce the program to three pilot sites in 1999.

3.2.4 Issues

Key informants reported a number of prevention issues:

- Across Canada, pregnant women and women of child-bearing age are not always routinely screened for alcohol and substance use problems. There is little agreement on which screening tool should be used, although the Alberta Medical Association recommends using T-ACE, citing a higher sensitivity and specificity than other screening instruments;

- An accurate assessment of substance use during pregnancy can be difficult to obtain from patients who are pregnant or are of child-bearing age and using alcohol/drugs;
- Where public and community awareness campaigns occur, they are often sporadic;
- There is a need for more of addiction treatment services offering treatment modalities that address women's needs and provide appropriate management of withdrawal for pregnant women.

3.3 Identification

The following section will expand upon identification issues.

Screening usually refers to determining the index of concern (i.e., "red flags") that warrant referral for diagnosis and assessment. In Canada, there are no standardized screening tools developed to help identify individuals who may have FAS/FAE. Some community agencies have developed their own screening tools. Most commonly used is the series of FASNET checklists that are designed to determine the need for referral, based on physical, cognitive, behavioural and social indicators specific to various age groups. Some professionals use Clarren and Astley's pre-diagnostic/assessment questionnaire as a screening tool.

The national toll-free Alcohol and Substance Use Helpline is operated by the Motherisk Program of the Hospital for Sick Children Toronto. This toll-free line provides information, counselling and referral, and is intended for women, their families and health professionals who have questions about the use of alcohol and other substances during pregnancy or breastfeeding. The Helpline is serviced by specially trained counsellors supported by a response team that includes doctors, pharmacologists and toxicologists.

Diagnosis usually refers to the medical diagnosis based on four sets of criteria established originally by Drs. Jones and Smith. Diagnostic schema most often used in Canada are:

- Institute of Medicine Diagnostic Criteria (Stratton et al., 1996);
- Diagnostic Guide for FAS and Related Conditions, the Four Digit Code (Astley and Clarren, 1997); and
- Original diagnostic criteria developed by David Smith, revised in 1989.

Ideally, diagnostic work is done as part of a comprehensive assessment carried out by a multidisciplinary team involving a physician – typically a pediatrician or geneticist to assess growth and dysmorphology – and a psychologist to assess the behaviours that would support the finding of central nervous system anomalies, such as mental retardation, learning disabilities or adjustment problems. Assessment usually refers to the psychological and developmental testing of a child in domains such as the physical, neuro-behavioural, social, cognitive, language and adaptive living, using a combination of methods and tools depending on the individual and their age.

Table 4: Jurisdictional Profile of FAS/FAE-related Activities: Identification

Identified Activities	YK	NT	NU	BC	AB	SK	MB	ON	PQ	NB	NS	PEI	NF
1. Physicians and psychologists or teams providing services for:													
▸ children	✔	✔	✔	✔	✔	✔	✔	✔					
▸ adolescents				✔									
▸ adults				✔									
2. Standardized official guidelines regarding diagnosis					✔								
3. FAS/FAE specific clinics/services offering comprehensive diagnostic and assessment services				✔	✔	✔	✔	✔					
4. Cognitive, social, behavioural and neuro-psychological assessment services for FAS/FAE affected:													
▸ children	✔			✔	✔	✔	✔	✔					
▸ adolescents				✔									
▸ adults				✔									
5. Physician training related to diagnosing FAS/FAE				✔	✔		✔	✔					

3.3.1 Diagnostic Services

In Canada, diagnosis is usually carried out by medical specialists, pediatricians, geneticists or dymorphologists. While most jurisdictions were able to identify at least one doctor who did diagnostic work in their jurisdiction, capacity is greater in western Canada. In some cities, those seeking a diagnosis go to genetics clinics. The shortage of diagnostic services is most felt in communities in northern Canada. It is difficult to find doctors who diagnose youth or adults. Where available, these services are often secured privately and costs are borne by the family.

Manitoba provides FAS/FAE diagnosis using the province's Tele-medicine links. An FAS/FAE diagnostic team is now available in the northern community of Thompson. Video conferencing technology allows the diagnostic team and their clients to consult with developmental genetic and therapeutic experts at the province's diagnostic clinic in Winnipeg.

3.3.2 Standardized Clinical Guidelines

There appears to be no consistent use of standardized diagnostic schema across the country. Alberta has developed clinical practice guidelines for diagnosis. The Alberta Partnership on FAS worked with the Alberta Medical Association to develop, publish and distribute the *Alberta Clinical Practice Guidelines on FAS* in 1999. One guideline focuses on preventive measures that will help healthcare practitioners increase their patients' awareness of the effects of alcohol consumption during pregnancy. Another guideline on diagnosis will help physicians recognize the syndrome and disorders associated with it, and also recommends steps to minimize secondary disabilities.

3.3.3 FAS/FAE-specific Clinics/Centres

There are few FAS/FAE-specific centres offering comprehensive diagnostic services across Canada and their services are generally not available to children over 18 (in some cases, 16) or adults. Examples of such centres include the Kinsmen Children's Centre in Saskatchewan, which operates an FAS/FAE clinic based on a multidisciplinary approach. The FAS/FAE team consists of a pediatrician, psychologist, physiotherapist, speech therapist and social worker. The team travels to remote communities to assist with diagnosis. Two satellite clinics in northern Saskatchewan started in October, 1999. Although included within broader services to children with developmental disabilities, Children's and Women's Health Centre in Vancouver offer a similar outreach service.

Recently, a multidisciplinary clinic was established in Manitoba. The Clinic provides on-site diagnostic and assessment services as well as tele-diagnostic services to Thompson. The Clinic provides diagnosis, assessment and treatment recommendations, as well as support for families to deal with the diagnosis and to connect with community resources.

The Motherisk Program at the Hospital for Sick Children, Toronto, has a special clinic for the diagnosis of FAS/FAE, involving pediatricians, psychologists, a neurologist, counsellors, a psychometrist, and addiction specialists.

3.3.4 Assessment Services

As with diagnosis, the availability of comprehensive psychosocial assessment services appears to be greater in western Canada. Assessments should typically take place within health, education, social service or justice systems. With the exception of the health care system, assessment related to FAS/FAE is very limited. Often children, including those affected by prenatal exposure to alcohol and other substances, are assessed within the context of infant development, early childhood development and child health programs.

Examples of assessment programs include the Child Development Centre in the Yukon which assesses children from 0 to 5 years of age for developmental delays, including children suspected to be affected by FAS/FAE. Referrals are made to physicians for diagnosis and complementary programs, that include work with individual children, family education, support and referral to other community resources as needed. With the exception of Newfoundland, the public education systems in all jurisdictions have not designated FAS as a separate special needs funding category. In 1998, the Department of Education in Newfoundland developed a special needs funding category, "Criteria G," addressing three less visible disabilities (autism, FAS/FAE and acquired brain injury) for identification and support within the school system. A medical diagnosis is needed to qualify for services.

3.3.5 Physician Training

Most respondents believe increased professional awareness and training are crucial to engaging at-risk women and to earlier interventions for children affected by FAS/FAE.

The Royal College of Physicians has prepared guidelines and conducted training on screening for alcohol problems. Health Canada is currently working with faculties of medicine, nursing and pharmacy from across the country to promote increased interfaculty training on substance use problems, including issues pertaining to pregnancy.

Special training for physicians to diagnose FAS/FAE is underway in several provinces across Canada. Along with the development of clinical practice guidelines, Alberta has implemented a two-part training program for its physicians. Continuing medical education presentations have been offered at various sites throughout the province. The first level course is aimed at increasing physician understanding of the effect of prenatal use, and diagnosis for the affected individual. The second level course offers specialized training to further prepare physicians to diagnose FAS/FAE and work within regional multidisciplinary teams.

The Manitoba College of Physicians and Surgeons has partnered with others to produce a videotape, "What Doctors Need to Know About Fetal Alcohol Syndrome". The tape provides information on the identification and diagnosis of FAS/FAE. It has been distributed to healthcare workers including family physicians, obstetricians and gynecologists across the province and shared with members of the Prairie Northern FAS Partnership. Alberta has distributed the tape to medical professionals across Alberta.

Also, the Motherisk Program in Toronto trains physicians, genetic counsellors, and medical students in the diagnosis of FAS/FAE.

3.3.6 Issues

Respondents raised a number of identification issues:

- Diagnostic services are largely unavailable. Where they do exist, the demand far outweighs the supply of doctors and assessment teams who can diagnose;
- Screening and referral for FAS/FAE within school systems is not routine and depends on the awareness of FAS/FAE by the administration, student support services and teachers;
- Difficulty of obtaining a diagnosis and needed services for children in child welfare, foster care, and adoption, is sometimes due to the inability of obtaining clear maternal drinking history required for a diagnosis;
- Not all Canadian physicians are trained to provide youth and adult diagnosis of FAS/FAE;
- There is a need for standardized terminology and diagnostic schema.

3.4 Intervention

The following section will expand upon intervention activities.

FAS/FAE has implications for individuals across the lifespan, therefore the necessary supports and services involve many disciplines and systems. Programs and services in health, education and social service systems are particularly critical for successful intervention. Due to the development of secondary disabilities associated with FAS/FAE, the corrections, justice and mental health systems often become involved. As the individual with FAS/FAE approaches adulthood, support from the employment/human resources system becomes important. Respondents also identified the need for ongoing support for family members.

It appears that few intervention services and programs that specifically address FAS/FAE exist across Canada. Most are concentrated within the health field and early childhood development and education programs. Many intervention programs are short-term, pilot or demonstration projects. Where it exists, intervention expertise often resides with individual professionals and frontline workers who work in agencies offering generic programming. Thus, it is difficult to determine the exact extent and scope of intervention activities specifically related to FAS/FAE across the country. Examples of intervention activities are discussed below.

3.4.1 Early Childhood

Infant development programs and early childhood development enrichment programs were identified in most jurisdictions. Most offer integrated services for children with developmental delays rather than focusing specifically on FAS/FAE. As an example, BC's Infant Development Program provides assistance for children from birth to three years with a known disability, or who are at risk for disability. When FAS/FAE is suspected (i.e. where there is known maternal drinking), these children are often referred and make up a large proportion of the caseload in some areas. The Building Blocks Strategy in BC is an early intervention strategy that focuses on children at-risk. In BC, three FAS/FAE-specific projects offer home visiting, education, group support and referral.

The Yukon Child Development Centre serves pre-school children with developmental and/or behavioural needs, including outreach services to children in outlying Yukon communities. Twenty to twenty-four per cent of the children served have FAS/FAE.

The Manitoba government funds the Pre-school Art Project. The project provides therapy classes for pre-school children. It is designed to assist children with FAS/FAE to develop school readiness skills and increased behavioural control.

In Toronto, Breaking the Cycle (BTC) is a community-based early identification and prevention program that is coordinated through a partnership model. The partners oversee this program through a steering committee. The program is designed to reduce risk and enhance the development of substance-exposed children (prenatal to six years) by addressing maternal substance use issues and the mother-child relationship. Mothers can access substance abuse treatment, health care, developmental and parenting support, counselling and information services through one location in downtown Toronto. BTC is a CAPC initiative that operates through a collaboration of the Canadian Mothercraft Society, the Jean Tweed Centre, the Motherisk Program of Toronto, the Children's Aid Society of Toronto, the Catholic Children's Aid Society of Toronto, and the City of Toronto Department of Public Health.

In Montreal, the Intervention Initiative on behalf of Addicted Mothers and their Young Children has been developed by the Research Group on Childhood Psycho-social Maladjustment, in partnership with the Research Team on the Prevention and Treatment of Addictions, the Centre for Psycho-education of Quebec, and local health services (*Centres locaux de services communautaires (CLSC)*). The experimental project is intended to offer integrated early intervention services to young women with children who have substance use problems in association with mental health problems, family violence and difficult economic conditions. It is a three-year project, which began with the identification of 130 mothers at risk. It is expected that during the course of the project, other *CLSCs* will be included.

The Support for FAS Children and their Families project in the Northwest Territories promotes the health, social and intellectual development of children with developmental disabilities associated with FAS/FAE, with specific focus on children 0

to 6 years of age and their families. The intent of the project is to promote understanding, education and community action around the prevention of FAS/FAE and facilitate the development of an effective community-based family support system. It is funded through Health Canada's CAPC Program.

Fetal Alcohol and Drug Effects Resource (FADER), a coalition of seven central interior communities in BC, also works with caregivers/parents/foster parents, and with pre-school children who are FAS/FAE-affected. Education on FAS/FAE and drug use is provided to adolescents, community groups, school staff, partner agencies and the general public. Workshops and support groups are offered on request; resources are available for loan from the resource centre.

3.4.2 Later Childhood

While there are few FAS/FAE-specific programs offered within public school systems, many teachers in the Yukon, BC, Alberta, Manitoba and Saskatchewan have received information on FAS/FAE. The governments of BC, Alberta and Manitoba have produced and distributed a guide on FAS/FAE for teachers. It contains basic information on FAS/FAE, classroom strategies on communication, learning and classroom management, and how to develop individual learning plans for the students. Alberta and Manitoba have followed up with province-wide training. An FAS/FAE consultant also works in the Winnipeg School District.

Alberta Learning has completed a revision of the kindergarten to Grade 9 health and life-skills programs to include information on the consequences of drinking when pregnant. They will also develop a teacher-training module for FAS/FAE prevention in the elementary to Grade 9 curricula. The Manitoba Department of Education has funded the Frontier School District to develop an FAS/FAE curriculum that has an Aboriginal cultural component to teach children on the importance of not drinking during pregnancy.

Examples of school programs for children affected by FAS/FAE include summer camps in BC and in the Yukon, and the toy lending library and community Four Plus and Skills for Life programs sponsored by the Yellowknife Catholic School Board. The Yellowknife Catholic School Board has an FAS/FAE coordinator who oversees these programs and collects statistics and other information.

The Learning Centre in Yellowknife has a private special needs school with a small ratio of children to teachers for kindergarten to Grade 9.

In BC, a major aspect of the CHIP initiative is to assist teachers to use effective classroom strategies for children affected by FAS/FAE in both the public schools and the schools operated by the First Nations Independent School Association.

In Manitoba, there is a pilot project for students ages 6 to 9 with FAS/FAE. The program is designed to explore the effectiveness of a variety of strategies, including yoga, token reinforcement, 1-2-3 Magic, use of icons, and others. As well, a variety of literacy and communication approaches are used. A multidisciplinary team addresses communication, social and literacy skills through individual and small group activities. Parents participate in a parenting component.

3.4.3 Adolescence

Respondents identified few programs that are specifically directed to youth affected by FAS/FAE. In BC, there is the newly formed FAS Activity Group for Teens, an employment training program; FAS Objectives for Community Understanding & Support (FOCUS) a job readiness program directed at young adults with FAS/FAE; and a six-month pilot pre-employment project. There is also some use of diversion planning and alternative sentencing in BC for youth affected by FAS/FAE who are involved with the justice system.

The FOCUS employment class emphasizes personal management skills such as stress, anger and time management for youth and adults with FAS/FAE. Students learn new ways to maximize their individual literacy and numeracy skills in preparation for specific job-related training. Once individuals are ready for supported employment, appropriate positions within the community are sought. Alternative training strategies and ongoing job support provide the tools necessary for both the employer and trainee to maintain a positive workplace relationship.

In Yellowknife, the YWCA has a program for young male adults affected by FAS/FAE with a supportive housing group home. As well, Manitoba recently opened a 20-bed residential youth addiction treatment unit that includes specific components for FAS/FAE-affected youth who reside in Winnipeg.

3.4.4 Adults

Respondents also reported that there are few examples of FAS/FAE intervention programs designed for adults affected with FAS/FAE. In the Downtown Eastside of Vancouver, Crabtree Corner offers a six-month "On The Job Mentoring Training" program for graduates of their birth mothers' program.

The Department of Justice in the Yukon is working to accurately identify the number of offenders affected by FAS/FAE so that appropriate services can be planned for them. The Department is also developing a needs assessment protocol with the assistance of the University of Washington, in Seattle.

Also in the Yukon, there is a buddy support leisure program. As well, the Options for Independent Living Society is preparing to open a pilot housing project for FAS/FAE-affected adults. An apartment complex from the Yukon Housing with a live-in manager will provide a supportive living environment for adults with FAS/FAE.

The Association for Community Living in Manitoba and NWT (Yellowknife) are developing specific programs to address the needs of adults with FAS/FAE and their families.

3.4.5 Family and Caregiver Support

Parents often require assistance with accessing services or advocating on behalf of their children. The FAS/E Support Network of BC and Greater Vancouver FAS Society provide consultation to families regarding FAS/FAE on a range of topics, including justice issues. The Northwest Territories has recently established a toll-free line to provide support and skill development to foster parents. As well, information helplines are available in some jurisdictions, for example SAFERA in Quebec, FASLINK and olderFAS in Ontario, and the Warm Line in BC. Helpline staff also provide advice and support to professionals and the public on a range of topics. Often the support is specific to issues or problems that callers are experiencing with an FAS/FAE-affected child in their care.

Respite programs are available in the Yukon. Respite care is provided to families and foster parents who need brief periods of relief from the needs of children in their care. While respite care is available in other jurisdictions, respondents report that it is often difficult to access due to administrative criteria based on IQ.

3.4.6 Issues

A number of issues concerning intervention activities were reported:

- Most intervention programs are designed to intervene with FAS/FAE children 0 to 6 years;
- There are few examples of programs directed to other age groups and they are primarily located in BC;
- There appear to be few respite programs for families and caregivers;
- Some youth and adult intervention programs that exist may not meet the needs of those affected by FAS/FAE;
- The full range of services, from assessment and diagnosis, through to education, employment, independent living, and life skills training, are not in place for adults and adolescents;
- Appropriately structured recreational and leisure time programs may not be available for most age groups. There are less opportunities for affected children and youth to participate in such programs.

3.5 Community and Systems Supports

Several provinces and territories have recognized the need for planning, technical support and support mechanisms in order to build the public and political momentum necessary to sustain FAS/FAE initiatives. Since FAS/FAE has implications for individuals, families and communities and requires comprehensive interventions across many systems, coordinating infrastructures, funding mechanisms, planning frameworks and training opportunities have been established.

The following discussion provides examples of mechanisms that support action on FAS/FAE or act as a catalyst for such action.

3.5.1 Support Mechanisms

BC's Ministry for Children and Families has three coordinating positions: a prevention coordinator, a consultant for early intervention with women with substance use problems, and an FAS/FAE medical consultant. The ministry also supports the Provincial FAS Consultation Group, a group representing stakeholders in the field. Membership includes community leaders, federal and provincial ministry representatives, First Nations, a cross-section of professionals, community-based coalitions and parents of children with FAS/FAE. The purpose of the group is to network, identify emerging issues, provide guidance regarding FAS/FAE policy and programs to the provincial consultants and government ministries, and to support community initiatives.

In 1998, the Alberta Minister of Social Services, the Saskatchewan Minister of Health and the Manitoba Minister of Family Services established the Prairie Province Partnership on FAS. This initiative is an alliance of provincial governments committed to develop, promote and coordinate comprehensive plans for the prevention of FAS/FAE as well as programs for intervention, care and support of people affected by FAS/FAE. Leadership of the partnership rotates annually. The provinces take turns hosting a provincial conference and producing a year-end progress report. Participation in this partnership is open to other jurisdictions. As noted earlier, this initiative has now been expanded into the Prairie Northern FAS Partnership with the inclusion of the Yukon, Nunavut and the Northwest Territories.

Respondents identified a number of coordinating bodies, such as regional FAS/FAE committees, provincial advisory groups, and inter-ministerial committees, with government, non-government or mixed representation. For example, the Alberta Partnership on FAS, created in 1998, is an alliance of partners with the purpose of developing, promoting and coordinating a comprehensive, culturally sensitive FAS/FAE prevention plan. Membership of the core group includes representation from provincial government ministries, regional boards and child and family service authorities, regional FAS/FAE committees, professional organizations, and community organizations. Also, there are two FAS/FAE provincial specialists who provide ongoing training, education and consultation throughout the province as well as a monitoring and evaluation consultant who works to develop community capacity in the area of

expected outcomes, indicators, measures, and evaluation. The Alberta Partnership on FAS is co-chaired by the Ministry of Children's Services and the Alberta Alcohol and Drug Abuse Commission (AADAC).

In Saskatchewan, the FAS Coordinating Committee was formed in 1993 and is made up of five ministries and 20 representatives. The Saskatchewan Institute on the Prevention of Handicaps coordinates the provincial FAS/FAE program. They also have a staff member who is responsible for FAS/FAE education and supporting community development with First Nations committees.

The FAS Coalition, spearheaded by the Manitoba Medical Association, is made up of 80 partners and has identified 12 themes to guide its coalition work. In Manitoba, a provincial coordination position, under the auspices of the Children's Secretariat, provides the opportunity to work across ministries.

A number of parent support or action groups across Ontario are attempting to form an Ontario parent coalition. Meetings have been held to determine how to work together and organize the coalition. In BC, parents have formed the Federation of Invisible Disabilities. The Federation advocates for needed services in the province and provides a communication link among parents.

The First Nations and Inuit Health Branch (FNIHB) of Health Canada, in collaboration with the Assembly of First Nations (AFN) and the Inuit Tapirisat of Canada (ITC), established the National First Nations and Inuit CPNP/FAS/E Steering Committee in November, 1999. This partnership was responsible for the creation of a national framework for the Fetal Alcohol Syndrome/Fetal Alcohol Effects Initiative. The framework was completed in April 2000, having received input from regional discussion and feedback sessions. Working groups were established to assist the committee in ongoing management of the initiative and to provide strategic direction and advice.

3.5.2 Funding Mechanisms

At the organizational level, 6% of survey respondents were engaged in funding activities to support FAS/FAE work. At the time of the survey, provincial government resources appeared to be less available in Eastern Canada.

Provincial governments in western Canada have provided more resources for specific FAS/FAE initiatives than elsewhere in Canada. The Prairie Northern FAS Partnership has provided leadership and a mechanism for jurisdictions to share resources and expertise in spite of limited financial resources. Alberta, Saskatchewan and Manitoba have established a Community Initiatives Grant Program. The program provides communities with seed money for local prevention projects to enhance community capacity and support for individuals with FAS/FAE.

Federally, CAPC/CPNP funding has supported a number of FAS/FAE-specific initiatives across the country. In February 1999, the federal government announced a three-year eleven million dollar national FAS/FAE initiative to enhance FAS/FAE-related activities across Canada. The National Crime Prevention Strategy also provides some regional funding for community-based FAS/FAE projects. Health Canada has also hosted National Forums to promote information sharing and knowledge development.

3.5.3 Planning Frameworks

Several provincial and territorial governments have developed strategic plans to direct and coordinate their work. In both Alberta and Manitoba, the strategic plans were designed under the auspices of the provincial government and involve key ministries. BC's current strategic plan was developed by the Ministry for Children and Families with direction from the Provincial FAS Consultation Group. It primarily outlines strategic initiatives that fall under the Ministry's mandate. An inter-agency group in the Northwest Territories, led by the Status of Women Council and the Yellowknife Association for Community Living, carried out a comprehensive needs assessment that became the basis for a strategic plan that was presented to the territorial government.

Federally, Health Canada, through the First Nations and Inuit Health Branch (FNIHB) and the Childhood and Youth Division of the Population and Public Health Branch, held regional consultation and feedback sessions across Canada. Other cross-Canada consultations have been held, led by Childhood and Youth Division of Health Canada.

3.5.4 Training

For the purposes of this report, training opportunities include both formal academic training and in-service or continuing education. Formal academic training is provided through post-secondary programs and institutions offering undergraduate, post-graduate, non-degree and extension programs. The purpose of this training is to provide in-depth specialized instruction to develop proficiency in the area of FAS/FAE. In-service or continuing education programs are offered through work settings to professionals and para-professionals for the purpose of upgrading FAS/FAE-related knowledge and skills. This form of education may be delivered through lectures, workshops or short courses arranged in house or in co-operation with other learning institutions.

Some examples of professional training opportunities include:

- A module on FAS/FAE and related information is integrated throughout the medical and dental students' curricula at UBC;
- At the Sal'i'Shan Institute in BC, FAS/FAE information and interventions are included in the core training for First Nations Community Health Representatives (CHR) and addictions workers in the community;

- College-level respite training programs are offered in BC and Manitoba;
- In Manitoba, the FAS Support Workers Certificate Course has been developed in partnership with the Red River Community College and the FAS Family Association.

In-service and professional development opportunities are more common across Canada than formal professional training. Generally, the western provinces have been most active in providing both types of training opportunities. All jurisdictions expressed the critical need to train professionals and frontline workers on all aspects of FAS/FAE (i.e., prevention, identification and intervention). Despite the demand, many jurisdictions do not offer training opportunities or have only recently begun to do so.

There have been a number of successful conferences and workshops held in several regions across the country. Each province involved in the Prairie Northern FAS Partnership takes the lead in organizing a provincial conference. BC has held a bi-annual conference on FAS/FAE for the last 10 years. Community-initiated conferences have also been held in BC, Alberta, Saskatchewan, Manitoba, Ontario, and Newfoundland and Labrador. Many professional organizations (e.g., in BC, the Special Education Association, Association of Alternate Educators and provincial judges) have included FAS/FAE on their conference agenda.

The FAS/E Support Network of BC has received funding from Health Canada for the first phase of a project to develop manuals on FAS/FAE, using a train-the-trainer approach and directed to parents and frontline workers. The first phase involved cross-Canada consultations regarding the approach and content for the manuals. In Alberta, in addition to the two-level physician training provided, interdisciplinary FAS/FAE training has been provided across the province. The Mi'Kmaq Friendship Centre in Nova Scotia has recently organized a train-the-trainer workshop for Aboriginal workers dealing with FAS/FAE.

Saskatchewan has piloted a training program for social service workers using distance video conferencing technology. The videotaped sessions have been edited into a teaching resource with an accompanying student manual. Another model geared to staff at young offender facilities assists workers to identify FAS/FAE. The training develops their ability to screen potential candidates for further professional assessment and to learn strategies for effective intervention. In Ontario, the Regional FAS Education Initiative was a one-year education and networking project funded by Health Canada's CAPC and Bell Canada. The primary purpose was to provide CAPC/CPNP and Aboriginal Headstart staff with knowledge on FAS/FAE. A series of recorded workshops were followed up by teleconferences. The Motherisk Program offers training in the diagnosis of FAS/FAE to physicians and other health professionals.

In BC, the training of physicians (family doctors and pediatricians) has been coordinated through the BC Pediatric Society, UBC Continuing Medical Education and Sunny Hill Hospital.

3.5.5 Issues

Respondents raised a number of issues regarding FAS/FAE community/systems supports:

- Coordination and support mechanisms appear to be sporadic across Canada;
- Resources dedicated to prevention, identification and intervention activities are limited;
- There needs to be an increase in ongoing FAS/FAE activities training;
- Training has not been uniform across the country and in many cases is still at the introductory level;
- Training in accredited programs for professionals, such as teachers, social workers, law enforcement officers, lawyers, addictions counselors, and corrections workers is less available;
- Training for Aboriginal workers needs to reflect Aboriginal perspective and culture.

3.6 Research

The need for research on prenatal exposure to alcohol was identified in a 1993 research workshop on the Prevention of Adverse Effects of Ethanol in Canada, organized by the Canadian Medical Society of Alcohol and Other Drugs in association with Health Canada, Dalhousie University and the University of Toronto. Many of the identified priorities still hold today.

While eight of the 13 provinces/territories reported at least one research project, research activities across Canada are limited. BC appears to be most engaged in research activities. Various agencies and institutions are involved in animal studies, prevalence surveys, needs assessments, social science surveys, program evaluation and policy research. Of these, needs assessments are the most common type. Examples of research are discussed below.

- The Faculty of Medicine at the University of British Columbia (UBC) operates a laboratory funded by the US National Institute of Alcohol Abuse and Alcoholism (NIAAA). Experimental animal studies have been conducted to examine the effects of alcohol use on the developing fetus.
- Two provincial FAS/FAE Delphi surveys were conducted in 1995 and 1999. The first survey established priority prevention and health promotion actions related to FAS/FAE; the second verified that priorities remained unchanged. It also provided direction for the provincial early intervention consultant's work.
- Professionals associated with the UBC and the BC FAS Resource Society have conducted a number of research projects over the years. The first Canadian incidence studies in communities were carried out in Northern BC and the Yukon, and within a small interior region of the province in the 1980s. In the early 1990s, a population-based study on Vancouver Island involving the training of family physicians and obstetricians in the use of a prenatal alcohol questionnaire (T-ACE) increased the awareness and referral of high-risk individuals (both women and

children), and suggested a high rate of prenatal alcohol exposure since it was sensitive to high-risk drinking behaviours. An incidence study to determine the number of youth with FAS/FAE in a forensic youth assessment facility was recently completed. The same researchers are planning a screening project at the pre-trial centres in the lower mainland. Another study at UBC examined vital statistics over a two-year period for the prevalence of prenatal exposure to alcohol and other drugs among infants and mothers who lived in the inner city of Vancouver.

- The University of Victoria has studied how the media is portraying issues regarding pregnancy and women's substance abuse. They are also involved with the FAS/E Support Network of BC in conducting a participatory action research project called "Adults Living with FAS" that looks at the needs of adults with FAS/FAE and community supports.
- Another participatory action research project, "Creating Solutions: Women Preventing FAS," is developing a model for a community policy response to FAS/FAE. The BC Women's Centre for Excellence in Women's Health has completed a policy research project that looks at the barriers to addiction services for pregnant and parenting women. Among the more significant barriers reported by participating women was the fear of being judged and shamed about their use.
- Research is being conducted by Manitoba Health on "Pregnant Women's Addiction Treatment Services" to determine the extent of services currently being provided for pregnant women with substance abuse problems, and to determine the specific needs of this population group. The results will form the basis for development of appropriate services to meet the needs of this population.
- Alberta completed a survey of physicians assessing their knowledge, attitudes and behaviour on FAS/FAE. The outcome of the survey was the development of clinical practice guidelines for physicians and other healthcare workers. Also, Alberta Health and Wellness, in collaboration with the Alberta Medical Association, is examining the feasibility of conducting a FAS/FAE prevalence study in a cohort of Grade 1 students in a region that has a high rate of self-reported maternal drinking.
- Other incidence studies are either under way (in the Yukon, under the guidance of the Bureau of Statistics) or just completed (in Newfoundland and Labrador, based on an analysis of data sources already in place).
- In Ontario, the Motherisk Program has tackled research questions such as the risks of binge drinking during pregnancy, child development after maternal cocaine use (with and without alcohol), and the use of meconium to diagnose FAS/FAE.
- In Quebec, the Centre of Excellence for Women's Health published a research paper, "Aboriginal Women and Maternity – Fetal Alcohol Syndrome," which discusses the issues of substance use and pregnancy as a health concern for First Nations women in Quebec. Another research project, "The Experience of Maternity Among Women Addicts," was initiated in Quebec by the Standing Committee on the Fight Against Addiction, an advisory body attached to the provincial Ministry of Health.

- Federally, Health Canada's Laboratory Centre for Disease Control will be enhancing its surveillance mechanisms for prenatal substance use. Health Canada has also undertaken a literature review in order to identify best practices for prevention, identification and intervention for FAS/FAE and other substance use during pregnancy.

3.6.1 Issues

Issues related to research activities as identified by respondents are as follows:

- There is a lack of Canadian incidence and prevalence data;
- Program evaluation to determine the effectiveness of prevention, identification and intervention programs is needed. One-third to one-half of the program survey respondents stated they did not evaluate their programs;
- Longitudinal studies to determine the impact of early interventions;
- A national research agenda with access to funding is needed.

3.7 Policy

Key informants indicated the need for ongoing policy activities in the following areas.

3.7.1 Priority Access to Services

In many regions of the country, women who are pregnant and have problems with substance use receive priority treatment for their substance use problems. In the Yukon, Alcohol and Drug Services is currently updating its policy on providing service to pregnant women who are drinking and is also examining ways to increase accessibility of their services for pregnant women.

3.7.2 Regulations Concerning Warnings

Some communities have by-laws requiring that warning signs on the effects of alcohol on the fetus be posted in local establishments selling or serving alcohol beverages. The BC Coalition for Warning Labels on Alcohol Containers lobbies federal and provincial governments to place warning labels on all alcohol beverages sold in Canada. The Yukon is the only jurisdiction where warning labels on the dangers of drinking alcohol during pregnancy are required on alcohol containers.

3.7.3 Community Policy Development

A BC community FAS/FAE policy development project, "Grounded in Hope", identified key "standards" or "policy directions" based on input from a broad group of stakeholders. The project has identified key steps to engage the community in policy development and is now implementing the policy directions identified.

In BC, extensive lobbying and advocacy work undertaken by a number of community teams is highlighted in the policy document, "FAS: Collective Action for Collective Solutions". The document is used as a basis for community groups to advocate for policy changes at meetings with Members of the Legislature, ministry representatives and provincial health authorities. Policy recommendations support a public awareness campaign, community-based FAS/FAE initiatives and public school curricula on FAS/FAE.

3.7.4 National Policy Position

Health Canada oversaw the development and distribution of the *Joint Statement: Prevention of Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE) in Canada* (1996). The statement was a collaborative effort of 19 national organizations, including Health Canada. It provides a set of definitions, principles and suggestions to guide FAS/FAE activities.

3.7.5 Other

Other policy initiatives:

- BC has developed hospital discharge protocols for substance-using women and FAS/FAE children.
- Yukon has amended the *Public Health and Safety Act* to provide for "the reporting by every medical practitioner of persons under their treatment suffering from Fetal Alcohol Syndrome."
- Yukon's legislation for children at-risk allows court-ordered treatment for pregnant women where there is reason to believe that the fetus is being exposed to alcohol.
- Resolutions have been adopted by a number of professional organizations, including the BC Medical Association, the Canadian Public Health Association, and the Registered Nurses Association of BC, on various matters pertaining to this issue.

3.7.6 Issues

Respondents raised a number of concerns related to FAS/FAE policy issues:

- The issue of IQ of 70 and the 18/19 age cut off as eligibility criteria for many social, education, and vocation services, needs to be addressed. Many children affected by prenatal exposure to alcohol have IQs over 70, but nevertheless have significant life-long needs;
- Child protection/custody and addiction treatment program policies need to reflect the needs of the family.

4. Respondent Opinions

4.1 Challenges and Gaps[2]

The challenges and gaps that are reported are ordered according to how frequently they were mentioned by key informants. Table 5 provides the frequency and a rank order of times mentioned. A brief synopsis of these themes and recommended actions is outlined below.

4.1.1 Professional and Frontline Workers' Knowledge

The most frequently identified gap was the lack of practitioner knowledge on FAS/FAE and its implications for practice across disciplines. Individuals also spoke of the need for training and professional development. More specifically, some professionals:

- Lack the knowledge and skills necessary to identify individuals with FAS/FAE;
- Tend not to understand the full nature of FAS/FAE, including how to effectively cope with and manage behaviours;
- Tend to not always work effectively with parents of children and youth who are affected with FAS/FAE; and
- Need to learn how to advocate within systems and across disciplines/systems of care.

Professionals in the education, addictions, medical and justice systems were identified as needing training on this issue. The need for training for physicians to help them identify and provide advice to women with substance use problems and diagnose FAS/FAE was identified.

Specific expertise in mental health issues (e.g., depression, sexual behaviours and knowledge of services available for referral purposes) as they pertain to persons with FAS/FAE is lacking.

2 This section is a summary of responses to question 2, "What are the challenges?" and question 4, "Where are the gaps and missing pieces?"

Table 5: Challenges and Gaps as Identified by Key Informants

Challenges and Gaps	Times Identified	Rank Order
Lack of professional/frontline worker's knowledge on FAS/FAE and implications for practice	39	1
Lack of identification, medical diagnosis and neuro-developmental/behavioural/psychological assessment	35	2
Lack of a full range of services for adolescents and adults	34	3
Lack of provincial/territorial government commitment, policy directives or leadership	34	3
Lack of support for caregivers/parents caring for children with FAS/FAE	32	4
Community/social attitudes and community denial	23	5
Lack of identification, support and appropriate treatment services for women	22	6
Gaps in public school/education system	22	6
Lack of financial and human resources to put the needed programs and services in place	21	7
Difficulties encountered when communities mobilize to address FAS/FAE issues	16	8
Lack of a structure or mechanism for sharing information	15	9
Lack of research activity and funding for research	14	10
Lack of recognition and practice regarding coordinated and integrated service delivery	14	10
Lack of public awareness/knowledge about FAS/FAE	10	11
Challenge of dealing with a complex issue that cuts across many disciplines	5	12
Lack of national coordination	5	12
Difficulties in providing needed services to small and remote communities	4	13

4.1.2 Identification Services

The lack of identification services (in particular medical diagnosis and neurodevelopmental/behavioural/psychological assessment) for adolescents and adults was mentioned often. Even where services exist, coverage and access are uneven and often do not extend to rural and remote communities.

There were calls for comprehensive diagnostic services and several informants stressed the importance of neurological/psychological assessment. This assessment is important since it helps to build a clearer picture of the capabilities of the person with FAS/FAE.

Coordinated team assessments by the appropriate combination of physicians, psychologists, occupational therapists, physiotherapists, speech therapists and mental health workers were recommended. Once a diagnosis has been made, follow up (i.e., intervention/care planning and putting services into place) was identified as the next course of action.

4.1.3 Services for Adolescents and Adults

Services for adolescents and adults with FAS/FAE and related effects are less developed in most jurisdictions. The lack of services for adolescents and adults includes:

- diagnosis/assessment;
- life skills training, including financial management, vocational and employment training, and opportunities to secure employment;
- addiction treatment services that take into account the nature of FAS/FAE;
- transition planning services for those able to move from dependency to adult living;
- recreational programs/services; and
- supportive adult living arrangements and housing.

Throughout the justice system, appropriate services for persons with FAS/FAE and related effects were mentioned as a gap often. Examples of needed justice services include alternative sentencing options, court procedures, and correctional programs, as well as programs that provide supportive supervision.

If a person with FAS/FAE has an IQ over 70, the lack of services across systems is exacerbated. It is important that services be determined by a diagnosis of FAS/FAE rather than by IQ.

4.1.4 Support for Caregivers/Parents

Respondents felt that parents and other caregivers are not being involved enough in decisions concerning their child. Similarly, there is a perception by parents that their skills and knowledge are not valued.

Foster, birth and adoptive parents need training and education on parenting a child with FAS/FAE. They need support with behaviour management, identifying areas of difficulty for the child, working with systems to access services, and advocating effectively for services. As well, there is a need for more mutual support for parents, (e.g., support groups and parenting programs) and better coordination of parent support, advocacy/action groups across the country. Most parent groups still work in isolation.

Respondents identified the lack of respite services for parents/caregivers, saying that these services must address the differing needs of parents and family. Support services are also needed for overall management of FAS/FAE issues, such as ongoing crises. The need for a national parent network was also identified.

4.1.5 Community Attitudes

Several informants spoke of the guilt, fear, and shame attached to acknowledging the presence of FAS/FAE in a community. They stressed that it is difficult to act on FAS/FAE issues if the community denies that FAS/FAE is a problem.

Respondents noted that there is still a social acceptance of alcohol consumption during pregnancy. It is difficult to promote abstinence or minimal use of alcohol during pregnancy if the social norms support drinking by women who are pregnant.

Respondents noted diverse public opinion concerning the most appropriate ways to work with pregnant substance-using women and birth mothers.

Many Canadians are still unaware of FAS/FAE and its causes and consequences. The need for a national public FAS/FAE awareness campaign was highlighted.

Respondents also identified the need to remove the stereotypes associated with children with FAS/FAE and society's perception of what constitutes a disability. These misperceptions were seen as contributing to the difficulty of putting appropriate interventions in place.

4.1.6 Identification and Treatment Services for Women

There is a lack of identification, support and appropriate treatment services for women at risk of alcohol and other drug use during pregnancy. Prenatal screening to identify high-risk levels of use during pregnancy, particularly by health professionals, is not routinely done. As well, there was a call for more effective programs to engage high-risk women and address their health, family, economic and social issues during pregnancy and after a child is born.

A lack of women-centred treatment services and aftercare programming that address women's concerns was clearly identified. These include: care for their children while they are in treatment, fear that their children might be taken away, personal shame and guilt, and societal blame.

There is a lack of treatment models/programs to address substance use problems among individuals with FAS/FAE. Individuals with FAS/FAE are at risk for substance use problems, but often drop out of treatment programs because of their memory deficits, learning disabilities and inability to engage in cognitive or insight-based therapy.

4.1.7 Public Education Systems

A number of gaps were identified in the programs and services of public education systems across the country. Respondents in the eastern provinces reported that there is less professional development and teachers' knowledge on FAS/FAE. Teachers need to be trained in behavioural management and to learn more effective strategies to deal with children affected by FAS/FAE. The need for a supportive educational environment, including setting realistic expectations in the classroom, was identified. Respondents also noted that education systems need to give greater attention to promoting positive values and attitudes towards children with FAS/FAE.

Education policies regarding assistance for children with FAS/FAE are lacking. Some informants requested that a specific FAS/FAE designation within special-needs education funding be allocated. It was suggested that parents' roles be recognized in the education planning for their children from K-12. Developmental assessment tools to more accurately determine the abilities of children with FAS/FAE are also needed.

4.1.8 Financial and Human Resources

Funding is fundamental to address the need for programs, services, training, coordination of efforts and support for community initiatives. Professionals often work *pro bono*.

Funding should be available for short- and long-term pilot projects and ongoing programs that maintain best practice interventions. Intensive long-term support throughout childhood, adolescence and adulthood is often required for those with FAS/FAE or related effects.

4.1.9 Mobilizing Communities

Respondents spoke about the challenges of getting and keeping a diverse group of people with different agendas focused on the main goals and tasks at hand. The complex and long-term nature of the problem also makes it difficult to keep up the momentum and motivation. Understanding the capabilities and varying stages of readiness of communities to address the issue requires particular expertise on the part of those wishing to mobilize communities.

4.1.10 Mechanisms for Sharing Information and Networking

Notwithstanding the National FAS/FAE Information Service operated by the CCSA, there is a need for more mechanisms to share information across the country. There also needs to be greater opportunities for networking and generating ideas on how to collectively address pressing issues.

4.1.11 Research

There is currently little Canadian data on the incidence and the prevalence of FAS/FAE. A lack of information regarding the incidence of FAS/FAE within specific groups was also noted. The ability to track changes in rates was noted as a deficiency. Data on prevalence of children affected by other substance use is less available.

FAS/FAE-related research activities are very limited. In particular, more research was called for in relation to the effectiveness of medications for children with FAS/FAE.

There is a need for more program evaluation and mechanisms for researchers to collaborate and to share findings.

4.1.12 Integrated Service Delivery

The importance of coordinated and integrated service delivery, coordinated care planning, and case management was stressed by the respondents. Comprehensive and coordinated services are needed across the life span. The inherent systemic problems facing affected persons and their families are exacerbated for those whose IQ is over 70; as well, services available for children past the age of six are not equally available or accessible within provinces/territories or across the country.

4.1.13 Other

Other challenges and gaps were identified less often:

- There is a general lack of public awareness and knowledge on FAS/FAE, its causes and the pervasiveness of the problems associated with FAS/FAE in our communities. There were calls for greater emphasis to be placed on public education and awareness. Coordination of such campaigns could be a joint effort of the various levels of government.
- FAS/FAE is a complex issue, cutting across many disciplines and requiring collaboration from many systems. It is neither easily recognized nor understood by the public and professionals alike.
- The need for increased national coordination as well as a national framework was identified.

- There are numerous difficulties in providing needed services to small, remote communities spread across a large geographic area. For example, when children go to larger urban centres for services (e.g., diagnosis and assessment), their communities are seldom equipped to provide required follow-up care on their return.
- While there are now more materials available to support FAS/FAE initiatives than ever, few have been translated into French.

4.2 Provincial/Territorial Priorities as Identified by Key Informants[3]

The priorities do not necessarily represent official government policy, but reflect the individual's perspective (i.e., parent advocate, health professional, community based person or government employee), the depth and breadth of their knowledge regarding FAS/FAE issues, and how connected they are to decision-makers within government and/or community organizations.

Priorities were placed into groupings and Table 6 illustrates the most frequently cited priorities by province or territory: professional development and training; prevention; provincial strategy and support; public/community education; identification; and intervention.

4.3 Elements of Progress and Success[4]

According to the key informants, the following are elements for success:

Leadership and Partnership

- guides the development of FAS/FAE activities.

Collaboration

- presents common messages, coordinated initiatives, shared expertise and learning.

Coordination

- establishes a focal point for FAS/FAE work, increases momentum, reduces duplication and gaps, and increases likelihood of sustained effort.

3 This section is based on question 3 of the key informant survey, "Have priorities been identified?"

4 This section is based on question 5 in the key informant survey, " Where has progress been made?" and question 6, "What is working and why? How is it sustained?"

Table 6: Provincial/Territorial Priorities as Identified by Key Informants

Priority Grouping (frequency)	YK	NT	NU	BC	AB	SK	MB	ON	PQ	NB	NS	PEI	NF
Professional development and training (11)	✓	✓	✓	✓	✓	✓	✓	✓	✓		✓	✓	✓
Prevention (10)	✓	✓	✓	✓	✓	✓	✓	✓	✓			✓	✓
Provincial strategy and support (9)	✓	✓	✓	✓	✓	✓	✓	✓	✓		✓		
Public/community education (9)	✓	✓	✓	✓	✓	✓	✓	✓	✓				✓
Identification (ability and availability of diagnostic services) (8)	✓	✓	✓	✓	✓	✓	✓		✓				✓
Intervention from infancy to adulthood (5)	✓	✓	✓	✓			✓		✓				
Cultural awareness and appropriate tools (4)		✓	✓	✓			✓				✓		✓
Research (4)		✓	✓	✓	✓		✓						
Inter-provincial collaboration (3)					✓	✓	✓						
Family support services (2)		✓	✓	✓	✓								
Treatment centres using a harm reduction approach (2)		✓	✓	✓									
Working with First Nation communities (2)					✓	✓							
Advocacy (2)		✓	✓	✓					✓				

Community Planning

- works within a common framework and with common purpose to strengthen local leadership, builds advocacy, and increases coordination.

Ongoing Public Awareness

- develops broader public and political understanding of the nature of FAS/FAE-related effects and the importance of sustained commitment.

FAS/FAE Resources

- contributes to increased public and professional understanding of the issues.

Professional Practice and Awareness

- enhances pre-service and continuing education on the range of FAS/FAE-related issues leading to a broadened capacity for care and treatment of pregnant women.

4.4 Recommended Federal and Provincial/Territorial Roles[5]

Table 7 highlights roles identified by respondents for federal/provincial/territorial governments in relation to FAS/FAE and the effects of other substance use during pregnancy.

4.5 Summary of Key Respondent Perspectives

FAS/FAE is preventable, but the circumstances that bring a woman to use alcohol or other substances during pregnancy are complex. Addressing this issue requires a sustained commitment from all stakeholders. This includes commitment, coordinating activities, direction on policy and practice, and making resources available. At the community level, a high degree of inter-agency collaboration to ensure that complex cases receive coordinated support is required. At the program level, commitment includes programming sensitive to client need.

5 This section is based on question 7 in the key informant survey, "What changes would you recommend for activities in your jurisdictions and why?" and question 8, "What (if any) role should the federal government play with respect to substance use during pregnancy in general? Specifically related to FAS/FAE?"

Table 7: Federal/Provincial/Territorial Roles Recommended by Key Informants

Recommended Role	Federal Role (# of times mentioned)	Provincial/Territorial Role (# of times mentioned)
Fund FAS/FAE initiatives across Canada	30	0
Provide access to current FAS/FAE information	19	4
Provide/support variety of direct services	14	33
Provide consistent leadership	13	4
Initiate a public FAS/FAE awareness campaign	11	9
Provide coordination	11	19
Support research activities	11	5
Develop a strategy that covers the life-span	11	4
Provide opportunities for networking	10	12
Establish an FAS/FAE mechanism/organization structure	7	0
Support ongoing education and training	7	20
Support the development of a national parent network	4	0
Promote and support Aboriginal leadership	3	4
Develop and support linkages to other initiatives	3	0

Key Respondents have noted that further work is needed in the following areas:

Information:

- access to information;
- continuous public education campaigns;
- widely available communication tools, such as videos, tele-medicine, internet, for the whole community.

Adolescents and Adults:

- appropriate employment training programs and supportive living options for adolescents and adults and seniors;
- leisure and recreation.

Parents, Caregivers and Advocacy:

- support for parents/caregivers such as respite care, telephone helplines;
- support for advocacy activities of families and caregivers;
- support for a national parent network.

Adoption:

- review of the adoption system in light of FAS/FAE;
- provide adoptive parents with the necessary financial support and access to services.

Planning and Coordination:

- consistent leadership;
- coordination of activities;
- a provincial coordinator in all provinces.

Professional Activities:

- regional/provincial conferences across the country;
- interdisciplinary professional training and development;
- professional training for physicians.

Service Delivery:

- early interventions;
- standardized screening, diagnosis and assessment tools;
- access to screening, diagnosis and assessment;
- continuity of care across the lifespan;
- appropriate treatment for clients in correctional facilities;
- appropriate treatment for clients in the mental health system;
- appropriate treatment for clients in the education system.

Alcohol/Drug Treatment:

- priority access to alcohol and drug/treatment for pregnant and high-risk women;
- culturally sensitive, harm reduction approach to treatment;
- pre-treatment planning;
- ancillary services (childcare, transportation).

Research

- prevalence and incidence studies;
- development of evidence for program planning.

Policy

- organizations need to address the specific needs of FAS/FAE clients in terms of policy.

Progress has been made, but more is required to bring FAS/FAE-related activities to the point where programming reflects the full spectrum of need across the country and across the life stages.

5. Profile of Activities

The activities that are listed below are not necessarily an exhaustive list within a particular province or territory. (Note: Several other provincial/territorial initiatives have been implemented since December 1999.)

5.1 Prevention

a) British Columbia

- Pregnancy Outreach Programs (POPs) are based on a comprehensive and integrated services model. The programs are primarily funded by the provincial government and some receive funding from the Canada Prenatal Nutrition Program (CPNP).
- Sheway is a comprehensive Vancouver based "one-stop shop" for pregnant substance-using women. Partners include the Vancouver/Richmond Health Board, BC Ministry for Children and Families, Vancouver Native Health, and YWCA.
- Surveillance and information is provided through the BC Reproductive Care Program's Perinatal Database Registry.
- FADER, a coalition of seven communities in the northern interior of BC, provides public education sessions, training and outreach to women at risk.
- Public awareness activities regarding FAS/FAE during National and Provincial Drug Awareness week (e.g., mall displays, poster contests, public forums, local media appearances, and newspaper articles) take place.
- Community-based public awareness efforts involving local media, including community meetings, workshops for professionals, regional conferences, and local public service announcements (PSA's) are ongoing.
- Low-literacy pamphlets and posters are distributed.
- The Liquor Distribution Branch targets drinking during pregnancy in liquor stores (e.g., posters, pamphlets, and messages on bags).

- There are community-based action groups working to address FAS/FAE issues on a number of fronts; groups usually have a number of sub-committees (e.g., education/prevention, diagnosis/identification/service needs).
- There are FAS National Crime Prevention Strategy projects with a broad primary prevention focus based on social/health determinants.
- The Community Healing and Intervention Program (CHIP) uses the strategies outlined in the Health Promotion Framework as a basis for a comprehensive approach to FAS/FAE among communities of Kinbasket First Nations.
- First Nations Independent School Association worked with BC Aboriginal Network on Disability Society to hold an FAS/FAE calendar contest.

b) Alberta

- Community capacity building projects within the Child and Family Services Authority Regions have been established.
- In Alberta, prevention work is interwoven into all components of the provincial strategy in the Alberta partnership. A public awareness campaign is raising awareness on FAS/FAE prevention through television/radio public service announcements, posters, newspaper stories, a newspaper ad campaign, liquor store bags, and liquor vendor window decals. The main messages in the campaign are: "When you are pregnant, no alcohol is best" and "Fetal Alcohol Syndrome is 100% preventable".
- Alberta has also initiated the "Born Free" campaign through a partnership between the Alberta Alcohol and Drug Abuse Commission, the Alberta Restaurant Service Association and the Alberta Liquor Store Association. Under the partnership, participating restaurants provide free non-alcoholic drinks to pregnant customers. Restaurants display signage that carries the same message as the provincial public awareness campaign.

c) Saskatchewan

- In Saskatchewan, community development initiatives have formed regional FAS/FAE committees.
- Baby Safe (Prince Albert) is a program for pregnant women who are using alcohol during pregnancy.
- Saskatchewan has a FAS/FAE public awareness campaign.

d) Manitoba

- Community FAS/FAE projects focus on the development of prevention and awareness messages as well as increased community associations and linkages.
- Aboriginal Health and Wellness Centre has a Community Outreach Program to provide culturally-based alcohol awareness information.

- FAS Baby Think it Over dolls have been introduced as part of a broad program to teach youth in schools on the risks of drinking during pregnancy.
- Rural northern consultations and seminars were undertaken.

e) Ontario

- The first FAS International Awareness Day was held.
- The Motherisk Program provides counselling and information through its toll-free Alcohol and Drug Healthline.

f) Quebec

- The Weimontashi Band Council is providing information related to alcohol use during pregnancy during nurses home visits to pregnant mothers.
- The Health Regional Authority of the Quebec Region has also developed a partnership project to work with addicted mothers.
- A public awareness campaign was planned in Centre de Santé Kujiuak during National Prevention Week.
- SAFERA disseminates information on FAS/FAE.

g) New Brunswick

- Ministry of Health staff linked with the Motherisk Program of Toronto to distribute a 1-800 number.

h) Nova Scotia

- Some prenatal courses speak on the importance of not drinking while pregnant.
- The Mi'Kmaq Native Friendship Centre has plans to promote awareness and education on FAS/FAE in Aboriginal communities. There are plans to develop a Web page and establish a 1-800 line.

i) Prince Edward Island

- A major project is underway in which physicians will use a prenatal psychosocial health assessment tool, the Alpha, that includes a number of different alcohol and drug questions. The tool was adapted by the University of Toronto.

j) Newfoundland and Labrador

- CPNP in Innu communities does not specifically address FAS/FAE, but covers issues such as how to have a healthy baby, good nutrition, exercise, looking after yourself, domestic violence and substance misuse.

- FAS/FAE awareness campaign in the Labrador region targets three different groups: medical practitioners, human service workers, and the general public. The region has adopted the approach that it takes a whole community to raise a child, as well as to support women and families in their attempts to not abuse substances during pregnancy.

k) Yukon

- FAS/FAE prevention initiatives through Alcohol and Drug Services are focused exclusively on treatment or support services for women who are drinking.

l) Northwest Territories

- Yellowknife Women's Centre Family Support Program runs an alternative Prenatal Program for women who are drinking during pregnancy.

m) Nunavut

- Some public awareness activities have taken place, but there is no specific programming related to FAS/FAE.

5.2 Identification

a) British Columbia

- Infant Development Programs and Child Development Centres are often key points of referrals for identification/assessment of children under three.
- Child development services exist throughout the province and Sunny Hill has specialist teams that offer diagnosis/assessment services.
- Recently the Greater Vancouver FAS Asante Centre in Maple Ridge received funding to begin offering diagnostic services and support for families.
- Mental health services provide outreach through mental health centres and specialized community-based services.
- Community-based groups (Maple Ridge, Quesnel) have received seed funding to develop a model for comprehensive diagnostic family centre/services.
- Psychoeducational assessments are available in BC school districts for children with learning problems, including children with FAS/FAE. Districts use designations to obtain funds for extra support services, e.g., teaching assistants.
- The Surrey pretrial project is underway under the guidance of Dr. James Ogloff, Simon Fraser University.
- Ministry for Children and Families, Programs Operation, Lower Mainland, will be hiring a project coordinator to train staff in screening and in referral for assessment.

b) Alberta

- Alberta Health and Wellness is working with the Alberta Medical Association to facilitate the implementation of the clinical practice guidelines and services for specialized, multidisciplinary team-based diagnosis and research on FAS/FAE.

c) Saskatchewan

- The Kinsmen Children's Centre at the University Hospital has an FAS/FAE clinic.
- Two satellite clinics (in North Battleford and La Ronge) were scheduled to start in October, 1999.

d) Manitoba

- Health Sciences Centre provides diagnostic and assessment services in Winnipeg. The Winnipeg FAS Clinic was approved to expand diagnosis to include children of all ages.
- Thompson FAS Clinic has a best practice model for FAS/FAE tele-diagnosis outreach in rural and northern Manitoba.

e) Ontario

- The Motherisk Program has a special clinic at the Hospital for Sick Children for the diagnosis of Alcohol-Related Birth Defects.

f) Newfoundland and Labrador

- The Department of Education developed three new criteria for the less visible disabilities. Criteria G focuses on autism, FAS/FAE and acquired brain injury. A medical diagnosis of FAS/FAE is still needed in order to access support.

g) Yukon

- Child Development Centre screens children 0 to 5 years for developmental delays, including those suspected to be affected by FAS/FAE.

h) Northwest Territories

- The Northwest Territories has two half-time pediatricians who do diagnosis, traveling into all regions and targeting young children.

5.3 Intervention

a) British Columbia

- Building Blocks is an early intervention strategy funded by the provincial government.
- The FAS/E Support Network of BC provides a Warm Help Line with phone support for the public and professionals.
- Special Needs Adoptive Parents (SNAP) provides support groups throughout the province (e.g., Victoria, Lake Cowichan, etc.).
- Other support groups for foster, adoptive parents and partners are provided by some of the community coalitions and services (e.g., FAS/E Support Network of BC, Crabtree Corner, Tri Cities FAS/FAE teams).
- Tri-Cities FAS/FAE Team is an activity group for teens.
- Greater Vancouver FAS Society and the FAS/E Support Network of BC provide consultation to families on a range of FAS/FAE topics.
- Crabtree Corner has a First Nations mentoring program where a representative from the birth moms' support group shadows the FAS/FAE coordinator in an on-the-job training placement for six months.
- FOCUS Employment Program is a training program for young adults with FAS/FAE offered at the College of New Caledonia. A six-month pilot pre-employment project for youth with FAS/FAE was delivered in Mission and within the Kinbasket First Nations Communities.
- Special needs preschool/daycare programs such as Building Blocks in Nanaimo and the Britannia Community Centre Preschool Program work with FAS/FAE children.
- White Crow Village is a privately owned summer camp for families and children with FAS/FAE at François Lake.
- The Infant Development Program provides developmental support, assessment and intervention for children 0 to 3.
- Diversion planning and alternative sentencing for youth affected by FAS/FAE who are becoming involved with the justice system is beginning.
- Multiple services are offered by the Kindale Association residential treatment program for youth who are involved with the justice system; there is specific programming for youth with FAS/FAE.
- CHIP works with public schools and First Nations Independent Schools to assist teachers in using effective classroom strategies for those affected by FAS/FAE; CHIP also has a youth worker who works with affected youth. CHIP has established a woman's craft co-op as an economic venture and produced a manual, "Story of CHIP".
- Vancouver Aboriginal Friendship Centre FAS/FAE program offers individual family consultation, counselling, parent support groups, and educational workshops for professionals and public schools.

- The Neonatal Abstinence Syndrome Native Foster Parent Program, operated by Vancouver Native Health Society, offers support to Aboriginal foster parents caring for infants experiencing Neonatal Abstinence Syndrome.
- The Federation of Invisible Disabilities has been formed with regional representation. FAS/FAE is a key invisible disability within the Federation's mandate. The Federation advocates for needed services and provides a support network. The Federation is developing a parent handbook to aid parents in understanding and advocating for services for their children with invisible disabilities.
- The M2W2 is a program for gays and lesbians in the Fraser Valley within the Ford Mountain Institution that provides services to sexual offenders. It is not focused on FAS/FAE specifically, but there are currently several inmates affected by FAS/FAE. There is a volunteer program component with complete wrap-around services for the inmates. When they leave the prison, a volunteer family assists them.

b) Alberta

- Replica STOP FAS programs (called Parent Child Assistance Programs) are being initiated in Edmonton, and Lethbridge and surrounding areas.

c) Saskatchewan

- Although not FAS/FAE-specific, there are a number of Aboriginal Headstart projects on-and off-reserve that provide intervention and support for pre-school children and their families.

d) Manitoba

- Pre-school Art Therapy Project in Portage la Prairie includes art therapy classes for pre-school children with FAS/FAE and peer support for their mothers. Goals are to strengthen school readiness skills and identify practices that are effective in working with children.
- STOP FAS is modelled after the Seattle Birth to Three Program. Norway House and the Aboriginal and Wellness Centre both have a STOP FAS program.
- FAS/FAE outreach program in Winnipeg provides community-based behavioural and developmental consultation, intervention, support and education to FAS/FAE children 0 to 6 and their caregivers. The program staff also provide consultation to rural caregivers.
- Addictions Foundation of Manitoba's 20-bed Residential Youth Unit opened in Winnipeg, September, 1999. Employees have received training related to FAS/FAE prevention and working with youth affected by FAS/FAE.

e) Ontario

- Breaking the Cycle (BTC) is a community-based early identification and intervention program that is coordinated through a partnership model involving Mothercraft, the Jean Tweed Centre, Motherisk Program, Children's Aid, and Toronto Public Health.
- Clinics for women with alcohol and other substance problems are offered across the province.
- Equaywuk (translation: the woman's group) in Sioux Lookout runs a Family FAS Support Project. The project serves the whole community, including off-reserve Aboriginal people, working with and advocating for families living with FAS/FAE.

f) Quebec

- In Montreal, an "Intervention Initiative on behalf of Addicted Mothers and their Young Children" has been developed by the Research Group on Childhood Psychosocial Maladjustment *(le Groupe de recherche sur l'inadaptation psychosociale chez l'enfant – GRIP)* in partnership with the Research Team on the Prevention and Treatment of Addictions *(L'équipe de recherche sur la prévention et le traitement des toxicomanies)*, the Centre for Psycho-education of Quebec *(Centre psycho-éducation du Québec)*, local health services *(CLSC)* for Hochelaga-Maisonneuve district, local health services for Olivier-Guimont and the Louis H. Lafontaine Hospital.

g) Yukon

- The Child Development Centre is available for all communities in the Yukon.
- Parent Support Group for parents with FAS/FAE-affected children is also available. The Group receives support from the Child Development Centre and the Fetal Alcohol Syndrome Society of the Yukon.
- Healthy Families' Program (HFP) is modelled on the Seattle Birth to Three Program supported through the Yukon Government, Family and Child Services Branch, as well as one of Yukon's First Nations Bands – the Kwantlin Dun Band. There is also a pilot HFP project in Carcross (a small community just outside of Whitehorse).
- Traditional Parenting Program is offered through Skookum Jim Friendship Centre.
- The Yukon Government Family and Children's Services supports the following:
  - An adult leisure buddy program for adults with FAS/FAE.
  - Respite care for caregivers with FAS/FAE.
  - A parent support group for foster parents with children with FAS/FAE.

- The Parent Social Support Program, run by the Yukon Association for Community Living, works directly with parents, often initiating contact via telephone.
- Correctional Service of Canada has a project looking at the issue of youth with FAS/FAE who are sexual offenders.
- Yukon Association for Community Living is developing the "Opportunity for Independence for Adults with FAS" project. The goal is to provide safe and stable housing for people with FAS/FAE.

h) Northwest Territories

- The Rehabilitation Team establishes a plan for interventions. Services are arranged through a local Community Health Centre.
- Aboriginal Headstart Program funds projects.
- Pediatric Rehabilitation Team includes a pediatrician, speech therapy, occupational therapy, and physiotherapy.
- Living and Learning with FAS Project offered through the Association for Community Living for ages 0 to 6 is used as a resource and for training related to FAS/FAE.
- FAS Children and their Families Project promotes the health, social and intellectual development of children with FAS/FAE. The project also develops audio-visual materials and other resources to promote the prevention of FAS/FAE and support for families dealing with FAS/FAE across the Northwest Territories.
- The Yellowknife Catholic School Board supports a Toy Lending Library and the Four Plus Program in the community. The Toy Lending Library supports family literacy as well. The Four Plus Program is an early intervention program through the Council of Disabled People that provides a trained aide to assist children with disabilities, including FAS/FAE-affected children.
- The Learning Centre is a private special needs school for children from kindergarten to grade 9.
- The YWCA program for young male adults affected by FAS/FAE includes a supportive housing group home. The YWCA also has a transitional housing program for young women, which includes FAS/FAE-affected young women.

5.4 Community Supports

a) British Columbia

- A provincial FAS/FAE prevention coordinator, whose key responsibilities include providing support for and coordinating the Provincial Consultation Group and its activities, also provides technical assistance to communities, acts as a central referral and information source regarding FAS/FAE, and supports community-based FAS/FAE training sessions. A compendium of FAS/FAE activities and the "Who's Asking?" report are also available.
- A provincial early intervention coordinator's key responsibilities include providing education and consultation to health and social service providers who work with pregnant women using substances.
- Provincial guidelines for the care of substance-using women and their infants (November, 1999), in collaboration with the provincial working group, are currently being developed as a training and best practices manual on pregnancy and substance use.
- A provincial medical consultant is currently working on a design and implementation of curriculum on FAS/FAE with the UBC School of Medicine.
- A provincial FAS/FAE consultation group, with representatives from agencies, government ministries (i.e., Health, Education and Children and Families, Attorney General, and Women's Equality), professionals, family members with affected children, and community-based task force/coalitions, work to address FAS/FAE.
- The Ministry for Children and Families has drafted a framework for prevention and support, and established an inter-ministry committee. The Ministry is also working in partnership with Health Canada as part of the Joint Management Committee for CPNP and CAPC.
- Attorney General (Liquor Development Branch, Server Intervention Training) has a component on alcohol and pregnancy.
- Education sessions on diagnosis were held at the BC Pediatric Association Annual General meeting in 1998, in partnership with Sunny Hill Hospital and UBC.
- Sunny Hill Hospital outreach teams train local physicians/psychologists to diagnose FAS/FAE in some regions.
- A three-hour FAS/FAE module in Foster Parent Orientation Curriculum has been developed.
- The Justice Institute of BC offers a course on FAS/FAE within the substance abuse certificate program. The Institute also provides an orientation to FAS/FAE for child protection workers and probation officers.
- A series of summer university credit courses on FAS/FAE are offered throughout BC (e.g., Burns Lake, Port Hardy, Williams Lake).

- The first phase of the FAS/E Support Network of BC's National Project on FAS/FAE started in July, 1999, with a series of community roundtables across the country networking with key players in each province.
- The FAS/E Support Network of BC conducts day-long to week-long training sessions, including follow-up days upon request.
- UBC Continuing Education in Health Sciences in partnership with Sunny Hill Hospital has organized a bi-annual provincial conference on FAS/FAE/NAS .
- Many school districts receive training on FAS/FAE, classroom management, and communication skills. A number of school districts have offered special regional conferences on FAS/FAE.
- Some of the school-based prevention workers and many of the community coalitions present information on FAS/FAE in junior and senior high schools. They also provide education sessions for teachers.
- The First Nations Education Steering Committee developed a booklet on FAS/FAE for teachers. Annual conferences take place in which FAS/FAE workshops are offered.
- Some informal organizations provide information on a range of topics on FAS/FAE/NAS. They have also formed the FAS/FAE/NAS Information Service Providers Committee and track requests for information as well as distribute a yearly report called "Who's Asking?"
- The University of BC (in consultation with the FAS/FAE medical advisor) has developed a module on FAS/FAE and related information that is integrated throughout the medical and dental students' programs.
- The Early Childhood Educators program offered at colleges has integrated FAS/FAE (particularly professional intervention skills and strategies) into its curriculum.
- At the college level, Special Education Assistant Programs have integrated FAS/FAE into their curriculum, targeting teaching assistants, childcare and social workers (e.g., Malaspina, Douglas College, Selkirk [Castlegar], Northern Lights [Chetwynd], Langara, Capilano and Kwantlen colleges).
- The Sal'i'Shan Institute in BC offers core training on FAS/FAE information and interventions for First Nations, community health representatives and addictions workers in the community.
- Respite training program – a college certificate course – focuses on families who have children with FAS/FAE.

b) Alberta

- There are two FAS/FAE provincial specialists who provide ongoing training, education and consultation support throughout the province – a provincial project manager and a monitoring and evaluation consultant.

- The Alberta Partnership on FAS is an alliance of partners with the goal of developing, promoting, and coordinating a comprehensive, culturally sensitive provincial plan for prevention, intervention, and care and support of FAS/FAE-affected individuals.
- The FAS/FAE initiatives are funded by the Children's Services Ministry. Contributions are provided through other partnering provincial ministries and community organizations.
- The Alberta Partnership on FAS has developed a Provincial FAS/FAE Strategic Plan, involving a broad cross-section of ministries and community organizations.
- The Children's Services Ministry is also developing a comprehensive professional education FAS/FAE framework. It will be very broad and will include health, social services, justice, teachers, etc. It is to be released in the fall of 2000.
- An FAS/FAE conference was held in Lethbridge.
- Alberta hosted an FAS/FAE conference as part of the Prairie Northern FAS Partnership.
- The Ministry of Learning is developing an in-service teaching package for teachers to manage children with FAS/FAE in classrooms.
- Through a partnership between the Alberta Medical Association and Alberta Health and Wellness, FAS/FAE training is being delivered to medical professionals.

c) Saskatchewan

- The FAS Coordinating Committee was formed in 1993.
- Saskatchewan Institute on Prevention of Handicaps:
  - Includes an FAS/FAE Program which supports the coordination of FAS/FAE provincial initiatives, and supports community development with First Nations committees.
  - FAS/FAE kits from the Institute and low-literacy materials.
- Saskatchewan Adoptive Parents Association is addressing FAS.
- Provincial Network for Early Intervention is supporting (0 to 6 years) interventions.
- Training by satellite for social workers in partnership with Ministry of Social Services and the Institute is available.
- Workshops for educators and other community workers are being held in partnership with the Prevention Institute and the Ministry of Education.
- Teleconference training of youth correctional workers throughout the province is available.
- Presentation to provincial judges on FAS/FAE has taken place.

d) Manitoba

- Child and Youth Secretariat is responsible for eight provincial ministries.
- Department of Justice Task Force on FAS/FAE is examining justice issues.
- Fetal Alcohol Association (for parents) includes:
  - Training (families as primary caregivers)
  - Advocacy
  - By Families For Families – series of five books
- Coalition of Alcohol and Pregnancy is a Winnipeg-based group previously called Committee on Alcohol and Pregnancy.
- Canadian Inhalant Conference was held.
- There is a FAS/FAE consultant within the Winnipeg School Division.
- Child and Youth Secretariat FAS Strategic Plan has been drafted; research and evaluation are key pieces.
- Ongoing inter-agency discussions on FAS/FAE are being held.
- Special Review of Education included a discussion of FAS/FAE.
- Committee on Tele-Diagnostic Work (with Health Sciences Centre) is addressing rural issues.
- "Reclaiming Our Voice: A Gathering of Mothers" sponsored by the West Region Child and Families Services with Seven Tribal Councils was held.
- Manitoba Medical Association and College of Physicians and Surgeons developed a CD Rom for all physicians as well as a day-long workshop on FAS/FAE diagnosis.
- There are plans to develop a multidisciplinary FAS/FAE curriculum, related to addictions process, identification, intervention and prevention.
- Respite Worker Certificate Course is a partnership project between Red River Community College, Addictions Foundation of Manitoba and the Association for Community Living.
- There is interdisciplinary and interfaculty education at the University of Manitoba.
- Workshop on Prevention and Early Interventions Key Influences Process is scheduled for Spring 2000.

e) Ontario

- Parent Support Groups include parent support or community action groups across Ontario.
- The Canadian Mothercraft Society in Toronto manages the Breaking the Cycle Initiative with several other community partners.
- Workshop on FAS/FAE was held at the Wabano Centre for Aboriginal Health in Ottawa (1998).

f) Quebec

- SAFERA is a newly formed francophone parent association established to provide information and public education on FAS/FAE.
- Abitibi-Temiscaming area has invited American experts on FAS/FAE to conduct information sessions on FAS/FAE.
- Sessions held in Kujiuak with health professionals, daycare and Aboriginal Headstart staff, focusing on FAS/FAE information and awareness.

g) Nova Scotia

- National train-the-trainer Aboriginal-led and focus workshop sponsored by the Mi'Kmaq Native Friendship Centre and Health Canada.

h) Prince Edward Island

- The Reproductive Care Program is a joint partnership with the Department of Health and the Medical Association and looks at FAS/FAE across PEI.

i) Newfoundland and Labrador

- The Newfoundland and Labrador Public Health Association is preparing a position statement on FAS/FAE.
- The Labrador Health Commission addiction health worker provides counselling, training and information sessions on FAS/FAE prevention.
- FAS/FAE workshops in Happy Valley, Goose Bay, and in Innu communities were held.
- A teleconference on awareness of FAS/FAE during the Drug Awareness Week was supported by the Public Health Association.
- A half-day workshop was sponsored by the provincial addiction services. People from addiction services throughout the province identified FAS/FAE as a priority and called for a provincial action plan.

j) Yukon

- Developed a comprehensive needs assessment and strategic framework within Family and Children's Services.
- Alcohol and Drugs Services has trained nurses, doctors and CHRs on brief screening tools.
- Yukon communities have received orientation on FAS.
- FASSY has scheduled FAS/FAE education workshops throughout the Yukon.
- The Department of Education provided training to teachers. Teachers are also represented on the FAS/FAE Committee.

k) Northwest Territories

- The Yellowknife Association for Community Living Family Support Project is supported through Health Canada, Brighter Futures.
- The FAS Community Team is organized through the FAS Support Project.
- There is a FAS Prevention Committee and an Inter-agency Committee.
- The Status of Women Council released its report entitled "Keeping Women and Communities Strong: Women, Substance Abuse and FAS/E."
- A FAS/FAE Working Group, with representatives of Coalition members, Health Boards and the Territorial Department of Health and Social Services, has developed a proposal for a gender-specific treatment program for women and their children.
- A comprehensive needs assessment was carried out and a strategic plan was developed. A second report called the "NWT Needs Assessment" was produced in collaboration with women from the community. The Coalition for New Futures for Northern Women (1997) emerged from the first report.
- FAS Project staff have organized a number of awareness workshops throughout the NWT.
- During National Addictions Awareness Week, a focus was on FAS/FAE.
- Inuvik Region has had community meetings and awareness activities. FAS/FAE mothers' support group was formed.
- Fort Simpson Region has had awareness workshops.

l) Nunavut

- Pauktuutit (located in Ottawa) provides support to Inuit and Innu families throughout the north.
- Pauktuutit hosted an FAS/FAE workshop for addiction workers, day care staff who are taking care of disabled kids.

5.5 Research

a) British Columbia

- In 1996, a Delphi Survey was conducted which determined provincial health promotion/prevention priorities for action. A second Delphi survey was completed in early 2000 to revisit these priorities and determine priorities for the Provincial Prevention and Early Intervention Coordinators' work plans.
- University of Victoria, School of Social Work, researchers Deborah Rutman, et al. have undertaken a study exploring policy alternatives and community-based responses for Aboriginal and non-Aboriginal substance-using women, which includes an analysis of legal discourse and print media depiction around pregnancy and substance abuse.

- A research project entitled "Adults Living with FAS/FAS: Building Communities, Strengthening Supports", co-sponsored by the FAS/E Support Network of BC and the School of Social Work, University of Victoria was aimed to provide adults with FAS/FAE and their support people with opportunities to voice their experiences, and to identify the kinds of day-to-day living supports that they use and need.
- A two-year participatory action research project through Healthiest Babies in Prince George has been completed. The key premise of this research, entitled Creating Solutions: Women Preventing FAS, was to develop a model for community policy response to FAS/FAE in Prince George. The researchers will be mentoring two other communities, Burns Lake and Smithers.
- A study of the incidence of FAS/FAE in the youth correctional system entitled Forensic Youth Assessment Study has been completed.
- Policy research on barriers to alcohol and drug treatment for pregnant and parenting women was completed by Nancy Poole and Barbara Isaac.
- Program and outcome evaluation research with the Sheway Program in Vancouver was completed. The study offers insights into a harm reduction approach when working with women who are pregnant and using substances. The results have been published by the BC Centre of Excellence for Women's Health.
- The University of BC continues to undertake basic science animal studies regarding the effects of alcohol use on the developing fetus.
- A study of socio-economic correlates and FAS/FAE has been conducted by Dr. Marie Hay and Jeannette Turpin.
- A pilot project will incorporate screening for FAS/FAE into the mental health screening at the pretrial centres in the lower mainland.
- A follow-up study of those who had participated in pre-natal screening in 1991 for alcohol use is being conducted by the UBC Health Promotion Unit.
- A longitudinal study was completed in 2000 of children prenatally exposed to varying amounts of alcohol and tobacco, and from a range of socio-economic backgrounds.

b) Alberta

- A survey of physicians regarding selected knowledge, attitudinal and behavioural indicators on FAS/FAE took place.
- The Alberta Partnership on FAS is evaluating the partnership and the progress made to date.
- The Alberta Partnership on FAS supports three pilot projects for high-risk populations that are intended to examine best practice approaches and models for preventing FAS/FAE.
- A proposal to establish FAS/FAE incidence in a representative Alberta community has been developed by Alberta Health and Wellness.

c) Saskatchewan

- A study looked at psychological functioning in adults with FAS/FAE, comparing them to adults with maternal PKU syndrome.
- A research study is underway involving adolescents with FAS/FAE.

d) Manitoba

- Survey of Needs (joint partnership with CAP and provincial government) took place.
- Manitoba study on pregnant and substance-addicted women is a joint venture between the provincial government and the Addictions Foundation of Manitoba.

e) Ontario

- The Motherisk Program conducts research into binge drinking and child outcomes, diagnostic criteria for FAS/FAE, new meconium test for *in utero* alcohol exposure, and the role of acetaldehyde in teratogenicity.

f) Quebec

- The Experience of Maternity Among Women Addicts, a research study initiated by the Standing Committee on the Fight Against Addiction, an advisory body attached to the Ministry of Health took place.

g) Newfoundland and Labrador

- 1996 and 1998 student drug use surveys in co-operation with the Atlantic Provinces took place.
- Statistics on prevalence of FAS/FAE in Newfoundland and Labrador are being compiled.

h) Yukon

- The Bureau of Statistics is carrying out a project to determine the incidence of FAS/FAE.

5.6 Policy

a) British Columbia

- Over 50 municipalities have introduced bylaws requiring warning signs to be posted in establishments selling alcohol.
- BC Coalition for Warning Labels on Alcohol Containers lobbies federal and provincial governments to place warning labels on all alcoholic beverages sold in Canada.

- Resolutions regarding the need for public education and warning labels was forwarded by the Union of BC Municipalities to appropriate Ministries.
- Resolutions regarding FAS/FAE have been adopted by a number of professional associations.
- Community FAS/FAE policy development project in Prince George identified key "standards" or "policy directions" that the community of Prince George supports.
- Provincial policy of priority addiction treatment for pregnant substance-using women is in place in all addiction services.
- Development of discharge guidelines for high-risk women and FAS/FAE/NAS children (Ministry of Health, Ministry for Children and Families, Children and Women's Hospital).
- Extensive lobbying/advocacy, undertaken by a number of community teams, is highlighted in the policy document, "FAS: Collective Action for Collective Solutions".

b) Alberta

- Priority access to alcohol and other drug treatment facilities for women is in place in all government-funded addiction agencies.
- A strategic policy review will be conducted across service sectors for children, adolescents and adults affected by FAS/FAE, and their families.

c) Saskatchewan

- Health districts responsible for addictions services are giving pregnant women priority in treatment facilities.

d) Yukon

- Alcohol and Drug Services is reviewing its policy on services to pregnant women who are drinking.

6. List of Resources

The following resources were identified by the key informants. The resource lists are grouped under the respective province or territory. The lists should be viewed as illustrative rather than exhaustive.

a) British Columbia

- "Fetal Alcohol Syndrome/Effects: A Framework for the Prevention and Support Draft". BC Ministry for Children and Families, May, 1999.

- "Who's Asking? Measuring Demands in BC for Information About Fetal Alcohol Syndrome/Fetal Alcohol Effects (FAS/FAE) and Neonatal Abstinence Syndrome (NAS)" (C. Legge). Report III, prepared for the FAS/FAE Information Service Providers Committee, July, 1999.
- "Moving Forward: FAS Activities in BC", BC Ministry for Children and Families, October, 1999.
- "Perinatal Substance Use Working Committee, Terms of Reference", BC Women's Hospital, 1998.
- "Philosophy Statements for the Care of Women in the Perinatal Period Who are Substance-Using". BC Women's Hospital, Substance Dependency Team Protocols, Draft 8, July, 1997.
- "FAS Community Action Guide: Working Together for the Prevention of Fetal Alcohol Syndrome" (1998), a joint project of the BC FAS Resource Society, the Aurora Centre at BC Women's Hospital and the Ministry for Children and Families. The guide includes a copy of a national report entitled It Takes a Community.
- "FAS and the Legal Process", a resource addressing the justice system.
- "FASNET" includes a case study on FAS/FAE for inclusion in a course for physicians and dental students at the University of British Columbia.
- "Grounded in Hope: Our Community's Policy Response to Fetal Alcohol Syndrome. A project of the Prince George FAS Community Coalition Network", sponsored by the Northern Family Health Society and supported by Health Canada (1998).
- "FAS and pFAS: Collective Action for Collective Solutions".
- "Community Prevention Guide", by Anne George, 1993 Guide to developing strategies for the prevention of FAS/FAE & NAS. (wic@ywcavan.org).
- "Guide for Parents, Teachers and Others Caring for Children with FAS/FAE or NAS", by Anne George, revised 1997. (wic@ywcavan.org).
- "Guide to Resources", by Anne George, revised 1996. Includes print materials, videos, associations, and programs. (wic@ywcavan.org).
- "Parenting children with Fetal Alcohol Syndrome: a guide for daily living" by Sara Graefe, sponsored by SNAP in BC and also distributed by the Adoption Council of Canada.
- "Guidelines for the Care of Substance-Using Women and their Infants" (BC Reproductive Care Program, November, 1999)

b) Alberta

- "Tri-Prairie Provinces Annual Report, Year One of the Prairie Province Partnership on Fetal Alcohol Syndrome (FAS), Fetal Alcohol Effects (FAE) and Alcohol-Related Birth Defects (ARBD)".
- "Alberta Partnership on Fetal Alcohol Syndrome, Terms of Reference", May 1, 1999.

- "Provincial FAS Initiative, FAS Community Projects First Status Report", March/April, 1999 (Revised June 17, 1999). The Status report also includes lessons learned from projects.
- "1999-2000 Strategic Plan on the Alberta Partnership on FAS (draft)", May 13, 1999.
- "Forever Home Strategy Session Summary Report". Session was held in Edmonton, Feb. 8-9, 1999, sponsored by the Ministry for Child and Family Services Authorities.
- "FAS/FAE Provincial Specialists Report for 1998-99", Debolt, D., Vandenbrink, M., prepared for Sharon Heron, June, 1999.
- "Clinical Practice Guidelines for Physicians and Midwives".
- In-service manual for teachers to care for children with FAS/FAE.
- "Fetal Alcohol Syndrome: a hopeful challenge for children, families and communities", by Carol Oliver and published by Health Promotion and Programs Branch, Health Canada, Calgary.
- "Born Free" information package (concerning provision of non-alcoholic drinks to pregnant women by participating restaurants).

c) Saskatchewan

- "Saskatchewan Institute on the Prevention of Handicaps Resource Catalogue", 1999-2000
- "FAS Resource Kits": one on Prevention and a second on Living and Working with Individuals with FAS, available from the Saskatchewan Institute on the Prevention of Handicaps.
- "FAS/E: A Community Perspective. Sharing Prevention and Intervention Strategies Regarding FAS/FAE Workshop Summary Report", 1998.
- "Saskatchewan FAS Coordinating Committee, Terms of Reference", October, 1997.
- "Community Development Initiatives": grant forms, guiding principles, application form and description of selected projects, 1997.
- "Annual Report on FAS/E Programming for Education and Prevention Project", submitted to Saskatchewan Health by Saskatchewan Institute on Prevention of Handicaps, March, 1999.
- "Parent FAS Newsletter", available from the Saskatchewan Institute on the Prevention of Handicaps.
- Training materials for professionals who work with young offenders who may have FAS/FAE, available from the Saskatchewan Institute on the Prevention of Handicaps.

d) Manitoba

- "Manitoba FASNEWS", Coalition on Alcohol and Pregnancy, Vol. 4, No. 2, Fall, 1999.
- "FAS/E Range of Services" list. April, 1997
- "Summary of Findings of the Manitoba Survey of Needs Regarding Fetal Alcohol Syndrome". Children and Youth Secretariat, Coalition on Alcohol and Pregnancy, and Community Action for Children, 1998.
- "The Manitoba Special Education Review: Equity, Capacity and Community – A Future Special Education in Manitoba". Proactive Information Services, Ltd., 1998.
- "Fetal Alcohol", a pamphlet published by the Family Association of Manitoba.
- Posters and brochures regarding the dangers of drinking while pregnant.
- Alcohol warning signs produced by the Manitoba Liquor Control Commission.
- FAS/FAE commercials.
- "One Drink Won't Hurt My Baby" brochure.
- "Inter-agency book on FAS on Parent Interventions" (Fall, 1999).

e) Ontario

- Canadian FAS/FAE-related reference lists compiled by Elspeth Ross, Adoption Council of Canada.
- "Breaking the Cycle: report of the development phase, June, 1994-March 31, 1995". A project of the Canadian Mothercraft Society, The Jean Tweed Treatment Centre, Metropolitan Toronto Children's Aid Society, Motherisk, Hospital for Sick Children.
- "Breaking the Cycle: A Chance for New Beginnings: Report I – the development phase".
- "Breaking the Cycle: A Chance for New Beginnings: Report II – learning from Year 1".
- "Breaking the Cycle: the Evaluation Report 1995-1997", February, 1998.
- "Working Together for a Better Tomorrow: Proceedings of the FAS Friends" Ontario Provincial Conference. Breaking the Cycle, Toronto, Canada. Jan. 23-24, 1999.
- 1-800 number for the Motherisk Program, Toronto Hospital for Sick Children.
- A magazine folder of FAS/FAE information resources, May, 1999.
- The Motherisk Web site (www.motherisk.org).
- Maternal Fetal Toxicology – A Clinician's Guide, 3rd edition. Editor Gideon Koren. Published by Marcel Dekker, NY. (in press)

- Adoption Council of Canada's information on FAS/FAE.
- FASLink, a listserv for parents.
- "FAS/E Parenting Manual" started by SNAP in BC and also distributed by the Adoption Council of Canada.

f) Quebec

- Pamphlet on FAS/FAE (English) developed by an Inuit nurse in Centre de santé Kujiuak.
- Pregnancy and Alcohol pamphlet.
- "Pregnancy and Alcohol in Question" produced by the Quebec College of Physicians and the Provincial Government's alcohol distribution agency, 1993.
- SAFERA is a francophone FAS/FAE parent association with its own Web site (http://www.safera.qc.ca/).
- The National Indian and Inuit Community Health Representatives Organization's (NIICHRO). Presentation by Janet Amos (http://www.total.net/~niichro/Prenatal/Pren5.html).

g) New Brunswick

- "Standards for Addiction Services" includes a component on women who come in for treatment and counselling.

h) Nova Scotia

- "Empowering Our Communities on FAS/FAE, Training Manual". Produced by the Mi'kmaq Native Friendship Centre, May, 1998.

i) Prince Edward Island

- "Prenatal Psychosocial Health Assessment". Adapted with permission from ALPHA Project 1993, Version May, 1998. PEI Reproductive Care Program (1999).
- "Enhancement of an Integrated Model of Prenatal Assessment and Care on Prince Edward Island", submitted by the PEI Reproductive Care Program. Revised March 12, 1999.

j) Newfoundland and Labrador

- "FAS Training Manual", a one-day introductory workshop.
- "FAS & FAE: A Report on Prevalence and Prevention Activities in Newfoundland and Labrador".

k) Yukon

- "Alcohol and Unborn Baby Kit".
- "Alcohol and Drug Survey" (1990).

l) Northwest Territories

- "Keeping Women and Communities Strong: Women, Substance Abuse and FAS/FAE: A NWT Needs Assessment. Status of Women Council of the NWT. May, 1996.
- "New Futures for Northern Women: women in recovery and healing – a pilot day program", prepared by the Coalition for New Futures for Northern Women, December 1998.
- Two public service announcements related to pregnancy and not drinking during pregnancy targetting teens and women.
- FAS Pamphlet for Community Health Nurses. Tips for talking with women about substance abuse issues.
- "Helping Children, Helping Families" video targets families who are raising children who may be affected by FAS/FAE.
- FAS/FAE poster directed at youth and linked to public service ads and several plain language posters.
- Labels on alcoholic beverage bottles since 1993.

Appendices

Appendix A: Key Informants Interview Questions

When answering the questions below:

- respond from a broad, **jurisdictional** perspective;
- consider and answer the questions separately for each section: **policy, research, and programming** activity;
- within each of the areas of activity note what is (or is not) occurring with respect to **prevention, identification** and **intervention** across the **life span**;
- in addition to FAS/FAE, consider the effects of other substance use and pregnancy – specifically, **opiates, stimulants, hallucinogens, cannabis, inhalants,** and **sedatives** – during pregnancy.

1. What is happening (current activities and recent past)?
2. What are the challenges?
3. Have priorities been identified? By whom?
4. Where are the gaps?
5. Where has progress been made (e.g., "strategic plans")?
6. What is working and why? How is it sustained?
7. What changes would you recommend for activities in your jurisdictions and why?
8. What role, if any, should the federal government play with respect to substance use during pregnancy? Specifically related to FAS/FAE?

Definitions and Terms

Fetal Alcohol Syndrome: (source: Stratton et al., USA Institute of Medicine, 1996)
Category 1 – FAS with a documented history of alcohol involvement by mother
Category 2 – FAS without a documented history of alcohol involvement

Fetal Alcohol Effects: (source: Stratton et al., USA Institute of Medicine, 1996):
Category 3 – partial FAS with a history of alcohol involvement
Category 4 – ARBD- physical anomalies only
Category 5– ARND – neuro-developmental disorders

Appendix B: Project Steering Committee Members

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